

What is the lived experience of patients with left ventricular assist devices during the COVID-19 pandemic? A qualitative analysis

Alessia Martina Trenta^{1,2,3}, Silvia Belloni⁴, Davide Ausili², Rosario Caruso⁵, Cristina Arrigoni⁶, Sara Russo⁷, Massimo Moro⁸, Ercole Vellone³, and Federica Dellafiore^{6*}

¹Heart Failure Unit, Cardiology Center Monzino IRCCS, Via Carlo Parea, 4, 20138, Milan, Italy; ²Department of Medicine and Surgery, University of Milano-Bicocca, Piazza dell'Ateneo Nuovo, 1, 20126, Monza, Italy; ³Department of Biomedicine and Prevention, University of Rome Tor Vergata, Via Cracovia, 50, 00133, Rome, Italy; ⁴Educational and Research Unit, Humanitas Clinical and Research Center IRCCS, Via Alessandro Manzoni, 56, 20089, Rozzano (MI), Italy; ⁵Health Professions Research and Development Unit, IRCCS Policlinico San Donato, Piazza Edmondo Malan, 2, 20097, San Donato Milanese (MI), Italy; ⁶Department of Public Health, Experimental and Forensic Medicine, Section of Hygiene, University of Pavia, Viale Forlanini, 2, Pavia, Italy; ⁷Department of Emergency Medicine, Humanitas Clinical and Research Center IRCCS, Via Alessandro Manzoni, 56, 20089, Rozzano (MI), Italy; and ⁸Health Professions Management Unit, Cardiology Center Monzino IRCCS, Via Carlo Parea, 4, 20138, Milan, Italy

Received 16 February 2021; revised 12 May 2021; accepted 14 September 2021

Background

During the COVID-19 outbreak, patients with left ventricular assist device (LVAD) faced several changes in their daily life. However, the effects of these changes on the patients' lived experiences are not still investigated.

Aims

The current study explored the lived experience of people with left ventricular assist device (LVAD) during the COVID-19 pandemic. During the COVID-19 outbreak, people with LVADs faced several changes in their daily life. However, the effects of these changes on the patients' lived experiences are not still investigated.

Methods and results

Qualitative data analysis was conducted employing the interpretative phenomenological analysis approach. We followed the Standards for Reporting Qualitative Research guidelines. Eight male participants with LVAD aged from 65 to 82 were interviewed. Overall, two main themes ('Worsening of psychological distress' and 'Moving forward') and eight sub-themes emerged from the qualitative analysis.

Conclusions

People with LVADs experienced feelings of worry and solitude related to the risk of being infected or not receiving adequate treatment due to changes in the healthcare system during the pandemic; however, they managed to move forward with their lives using different strategies for dealing with the difficult situation.

Keywords

Left ventricular assist device • Coping strategies • COVID-19 pandemic • Interpretative phenomenological analysis

Implications for practice

- COVID-19 pandemic impacted left ventricular assist device (LVAD) patients' experiences worsening their psychological distress.
- Targeted interventions are needed for providing psychological support to these patients and guaranteeing.
- A re-organization of the healthcare delivery system is needed for guaranteeing continuous monitoring and care to patients with an LVAD.

* Corresponding author. Tel: +39 0382 987282, Fax: +39 0382 987290, Email: federica.dellafiore@unipv.it

Published on behalf of the European Society of Cardiology. All rights reserved. © The Author(s) 2021. For permissions, please email: journals.permissions@oup.com.

Introduction

The COVID-19 pandemic—which so far caused more than 28 million confirmed cases and roughly 1 million deaths globally—profoundly modified healthcare delivery worldwide.¹ Hospitals were reorganized to prioritize access to care for patients with COVID-19 or other urgent conditions, while telemedicine services often substituted outpatient clinics, and all non-urgent visits and diagnostic procedures were postponed.² Consequently, the pandemic had a significant impact on people affected by chronic conditions, including people with a left ventricular assist device (LVAD), whose healthcare needs have been overshadowed by the issues caused by the COVID-19 pandemic.³

Left ventricular assist devices are life-saving heart pumps utilized to support the left ventricle at the end-stage of heart failure. These devices are implanted internally and powered by external batteries managed by the patient.⁴ Therefore, LVAD placement requires frequent outpatient visits to assess the health status and implement specific self-care behaviours to maintain psychological and physical well-being.⁴ Specifically, living with an LVAD requires a complex process of adaptation.⁵ At first, patients need to develop skills for managing the device (e.g. changing its batteries, monitoring its functioning) and learning specific self-care behaviours that allow them to integrate the LVAD in their everyday life and keep their disease under control.⁶ Then, the process consists of creating new daily routines with the device until new normality is reached.⁶ However, this adaptation process often causes distress in patients, leading to psychological issues that can persist throughout time.⁷

During the COVID-19 outbreak, LVADs patients were particularly at risk because of their clinical condition and vulnerability.³ Furthermore, these patients had to face several challenges, such as the transition from care delivery systems to telemonitoring programs realized to reduce hospital exposure as much as possible.^{3,8} At present, data about the effects of these changes on LVAD patients' lived experiences are lacking. Having this information could facilitate healthcare providers in the identification of LVAD patients' needs during a pandemic and, consequently, in the development of effective interventions. Therefore, the current study aimed to explore the lived experiences of people with LVADs during the COVID-19 pandemic.

Methods

Design, study population, and data collection

This qualitative research was conducted following the interpretative phenomenological analysis (IPA) approach.⁹ A qualitative analysis was employed to explore LVAD patients' peculiar experiences during the COVID-19 pandemic, and it could provide a unique contribution to research in this field,^{10,11} as it reflects an in-depth inquiry into the lived experiences of patients with LVADs in the COVID-19 era. Considering that the presence of LVAD determines personalized and specific health and life needs,⁶ an in-depth analysis was necessary to understand these specific experiences also during a critical situation such as the COVID-19 pandemic.

Participants were recruited in a Cardiac Research Hospital in Northern Italy through purposive sampling, selecting patients with heart failure with an LVAD, able and willing to provide study consent, and Italian speaking. Patients with full-blown cognitive impairment were excluded. Patients receiving ambulatory care after LVAD implantation were recruited, and a research nurse contacted potential participants by phone, informing them about the aim and procedures of the study. To guarantee transparency throughout all study, we followed the Standards for Reporting Qualitative Research guidelines.¹²

The data collection was performed using semi-structured questions to explore patients' specific lived experiences during the particular period of the COVID-19 outbreak. A nurse experienced in qualitative research conducted semi-structured in-depth interviews. The interviews were performed online because social distancing rules prevented face-to-face encounters and were audio-recorded. Additionally, the participants' sociodemographic profile was collected at the start of the interviews.

Specifically, open-ended questions were utilized to explore significant arising points on participants' experiences during the pandemic.⁹ Therefore, LVADs patients provided a detailed description of their life-world and personal experiences in these particular circumstances. Specifically, researchers explored participants' perceptions about changes in daily life caused by COVID-19, trying to emphasize their emotions, challenges, and expectations. Probing questions were used to clarify some relevant aspects and boost the depth of discussion. Examples of the questions are presented in [Table 1](#). The interviews were not interrupted until participants had finished, or open-ended questions no longer gave rise to any new information (i.e. data saturation was achieved).¹³ All interviews were audio-recorded and transcribed verbatim by the research team and reviewed by the interviewer to guarantee accuracy.

Table 1 Interviews' guide for patients with left ventricular assist device

- Could you tell me about your experience with the LVAD device, and how is living with it?
- Could you speak about the consequences of the LVAD device in your everyday life?
- Can you describe the impact that the current health emergency caused by COVID-19 has had on your life and LVAD management?
- How your everyday life has changed following this emergency?
- What difficulties are you facing? What strategies are you adopting to cope with this situation?
- Is there anyone who is helping you to manage your health status? Have you asked for support from any associations?
- What are your concerns regarding this health emergency?
- How do you live the restrictions for social distancing?
- What are your thoughts and feelings for the future?

LVAD, left ventricular assist device.

Data analysis and rigour

A qualitative text data was analysed with the IPA methodology⁹ to obtain an in-depth understanding of patients' lived experiences during the COVID-19 period. The IPA consisted of translating identified leading themes into significant and relevant narrative descriptions of the phenomenon under examination rather than generating theories from the data given previously to identify hypotheses.⁹ Two independent researchers, having specific qualitative analysis training, conducted the data analysis. They read the transcript several times to acquire a deep understanding of meanings, selecting significant phrases, and coding them in themes and subcategories to capture essential features and relevant meanings related to preliminary research questions. Afterwards, themes were linked to each other to establish a coherent and organized thematic account of the phenomenon, according to the IPA methodology.⁹ Following there is an example of the analysing process and development of themes and sub-themes: after the data analysis of transcribed interviews, the researchers underlined the most significant sentences on a similar concept, such as the negative feelings experienced by LVAD patients. In particular, feelings of fear, worries, awareness of their health fragility and concerns arose, and were gathered to identify the first theme.

Rigour in data analysis was guaranteed by applying the process of credibility, transferability, and dependability.¹⁴ Before data analysis, the 'bracketing' technique was applied—a critical reflection by researchers who have to make notes on their preconceptions regarding hypothesis under investigation, suspending judgement, and focusing on what is presented in the transcript data.¹⁵ An additional and independent researcher performed the analysis validity checks and interpretations. Redundant and/or overlapping themes were removed and assembled to define a list of pre-ordained and subordinate topics.¹⁵ Afterthought, clear individual summaries were provided for each interview to ensure 'transparency and coherence' and allow methodological trustworthiness.¹⁶ All the results were translated from Italian into English according to the recommendations for an optimal representation achievement of participants' experiences,¹⁷ and an English expert reviewed the contents.

Ethical considerations

The study was conducted in accordance with the Declaration of Helsinki principles, and ethical approval was obtained by the Institutional Board Committee of the hospital where the investigation was performed. Before taking part in the study, participants provided informed consent about their participation and their agreement to the interviews' audio recording. A code number (e.g. P1, P2, P3) was assigned to each participant to guarantee anonymity and confidentiality throughout the study, deleting identifying information from the transcripts. The audio-recorded

interviews and transcripts were saved on a password-protected computer. Patients were informed that participation was voluntary, their confidentiality would be ensured, and they were entitled to leave the study at any time.

Results

The sample consisted of eight male participants whose NYHA (New York Heart Association) class varied from II to III, and ages ranged from 65 to 82. [Table 2](#) shows the principal sociodemographic and clinical profile of participants enrolled in the study. Data saturation was reached after interviewing seven participants. Then, one more interview was conducted to confirm the themes' redundancy.

Two main themes were developed from the interviews' qualitative analysis, describing people with LVADs lived experiences during the COVID-19 pandemic: 'Worsening of psychological distress' and 'Moving forward'. An accurate description of the themes and sub-themes is described below ([Table 3](#)).

Theme 1: 'Worsening of psychological distress'

This theme reflects the negative feelings that participants experienced during the COVID-19 pandemic due to their health conditions and social circumstances determined by the situation. Specifically, they described a sense of constant concern with the isolation caused by regulations issued to contain the novel coronavirus spread.

When the pandemic developed, participants were vigilant since the beginning, experiencing growing worries for managing the general situation. Patients expressed anguish about the massive number of victims and the transformation of the hospitals, which were locked down to visitors, preventing loved one's visits to hospitalized patients: 'I was concerned even since January. (...) There is a constant concern. (...) Not only about death—because death happens at any moment—but ... a man needs to be honored. But in this way, (the fact) that you can't see people ... seeing all those trucks carrying dead people was really awful' (P1).

The awareness of their health fragility strengthened this sense of concern among study participants because they felt 'different from other people' (P2), and knew that the COVID-19 was very dangerous for their health condition: 'I'm aware that, even a flu can be dangerous for me, considering my health problems' (P1). Furthermore, this worry

Table 2 Sociodemographic characteristics of participants with left ventricular assist device

| Interview number | Gender | Age (years) | Marital status | Geographic area | Profession | Education | NYHA class | LVAD stay (years) |
|------------------|--------|-------------|----------------|-----------------|------------|----------------|------------|-------------------|
| 1 | Male | 65 | Married | South | Retired | Middle school | II | 3.5 |
| 2 | Male | 73 | Married | North | Retired | Primary school | III | 3.5 |
| 3 | Male | 69 | Widow | North | Retired | High school | II | 5 |
| 4 | Male | 73 | Common law | South | Retired | Primary school | II | 3 |
| 5 | Male | 72 | Married | North | Retired | Middle school | III | 5 |
| 6 | Male | 82 | Married | North | Retired | Primary school | II | 5 |
| 7 | Male | 67 | Married | North | Retired | Middle school | II | 1 |
| 8 | Male | 79 | Married | South | Retired | Primary school | II | 2 |

LVAD, left ventricular assist device; NYHA, New York Heart Association.

Table 3 Description of categories and subcategories

| Main categories | Subcategories | Quotations |
|--|---|--|
| <p>'Worsening of psychological distress'</p> <p>This theme reflects the negative feelings that participants experienced during the COVID-19 pandemic due to their health conditions and social circumstances determined by the situation. Specifically, they described a sense of constant concern with the isolation caused by regulations issued to contain the novel coronavirus spread</p> | <p>'Sense of concern': when the pandemic developed, participants were vigilant since the beginning, experiencing growing worries about the management of the general situation</p> | <ul style="list-style-type: none"> • 'I was concerned even since January. (...) There is a constant concern. (...) Not only about death—because death happens at any moment—but ... a man needs to be honored. But in this way, (the fact) that you can't see people ... seeing all those trucks carrying dead people was really awful' (P1). • 'I have a huge fear, a constant anguish. I barricaded myself in my home, fearing to meet people who might have the virus' (P6). |
| | <p>'Awareness of their health fragility': the sense of concern was strengthened by participants' awareness about the health fragility caused by their clinical conditions</p> | <ul style="list-style-type: none"> • Participants felt 'different from other people' (P2), • 'I'm aware that even a flu can be dangerous for me, considering my health problems' (P1). • 'I'm afraid that something serious could happen to me (...), for difficulties in reaching the hospital in time for being treated. (...) The fact that in the hospitals there is a sort of invasion of COVID-19 patients makes me anxious. (...) If I would be sick, going to the hospital represents a risk' (P3). • 'I'm afraid that I might need to go to another hospital (rather than the reference centre) and I might not receive proper care for my special condition' (P5). |
| | <p>'Sense of abandonment': the delay of routine visits and procedures, which were postponed for prioritizing urgent activities, worsened the psychological distress creating a sense of abandonment</p> | <ul style="list-style-type: none"> • 'When I was discharged from the hospital, I began to go to the gym (in a rehab center), but when this thing (the outbreak) happened they suspended everything' (P5). |
| | <p>'Distress for social isolation': the isolation caused by regulations about social distancing was a great source of distress for participants</p> | <ul style="list-style-type: none"> • 'I reorganized my life to remain at home' (P5). • 'What I miss is a social gathering, because I live for people, I live for social contacts. (...) A few days ago, I cried for my nephew because he was on the stairs and said «Grandpa, I'd like to hug you». These things are heavy' (P1). |
| <p>'Moving forward'</p> <p>Despite the psychological distress exacerbated by the pandemic, participants were able to perform some self-empowerment and coping strategies that helped them deal with the current situation, reducing the feelings of worry and isolation and allowing them to move on with their lives</p> | <p>'Taking control': participants tried to cope with the fear of not reaching the reference centre by taking control of their health management</p> | <ul style="list-style-type: none"> • 'If something is wrong with me (with my health conditions) I immediately call the reference center. I try to deal with the problem promptly, without waiting for worsening' (P3) • Participants reported they tried 'to do the best to feel good' (P8) |
| | <p>'Adapting to the circumstances': recognizing the rapid growth of the pandemic, participants realized they had to cope with the situation by adapting their life to the circumstances</p> | <ul style="list-style-type: none"> • 'I understand I have to adapt my life to what is happening, and I am trying to do my best' (P2). • 'Only a few things changed (because of the outbreak), but I am trying to adapt to the situation' (P2) |
| | <p>'Resorting to a positive attitude': in order to facilitate the acceptance and adaptation process, participants resorted to a positive attitude</p> | <ul style="list-style-type: none"> • 'The positive aspect is that now if you call someone by phone, s/he will certainly answer because everybody is at home. Before (the outbreak), maybe a |

Continued

Table 3 Continued

| Main categories | Subcategories | Quotations |
|-----------------|---|--|
| | | <p>person could be busy, while now everyone is available' (P1)</p> <ul style="list-style-type: none"> • 'You set up future goals, for not thinking about the present. For instance, I'd like to go to the mountain, so I'm planning a hike' (P3) • Participants believed that divert thoughts towards positive things and 'not thinking about the situation' was 'the right medicine to pass the time and get out of boredom' (P8) |
| | <p>'Support from families and healthcare providers': seeking support from families and healthcare providers was another crucial strategy used by participants to maintain stable their health status and pursue their goals</p> | <ul style="list-style-type: none"> • 'In my family I found the best collaboration. Their support was crucial for me' (P7) • 'I had trouble with medicating my wound, because my wife is not expert in this field. But now some nurses come to my home three times a week, and in this period it's a huge help' (P1) |

was increased by the fear that, in case of emergency, restrictions in transfers across different regions could prevent access to the reference centre. Patients expressed trust in the reference centre, recognizing specific competencies, whereas scepticism and uncertainty towards other hospitals were reported: *'I'm afraid that something serious could happen to me (. . .), for difficulties in reaching the hospital in time for being treated. (. . .) The fact is that in the hospitals, there is a sort of invasion of COVID-19 patients makes me anxious. (. . .) If I would be sick, going to the hospital represents a risk'* (P3).

Furthermore, another cause of concern was the delay of routine visits and procedures, which were postponed to prioritize urgent activities. This situation led to a sense of abandonment among participants in carrying on with their care paths, as reported by a man who had to give up on physiotherapy: *'When I was discharged from the hospital, I began to go to the gym (in a rehab center), but when this thing (the outbreak) happened they suspended everything'* (P5).

In addition to worries, the isolation caused by regulation about social distancing was a great source of distress for participants. At first, patients had to quarantine at home as a preventive safety measure: *'I reorganized my life to remain at home'* (P5). However, the quarantine harmed their state of mind, limiting the possibility of meeting relatives, and causing a sense of general solitude: *'What I miss is a social gathering, because I live for people, I live for social contacts. (. . .) A few days ago, I cried for my nephew because he was on the stairs and said <<Grandpa, I'd like to hug you>>. These things are heavy'* (P1).

Theme 2: 'Moving forward'

Despite the psychological distress exacerbated by the pandemic, participants were able to perform some self-empowerment and coping strategies that helped them deal with the current situation, reducing the feelings of worry and isolation and allowing them to move on with their lives. Accordingly, the second theme is named 'Moving

forward', highlighting the main LVAD patients' resources deployed to face COVID-19's challenges.

At first, they tried to cope with the fear of not reaching the reference centre by taking control of their health management. For instance, they improved the monitoring of signs, symptoms, and LVAD functioning to detect any complication at an early stage: *'If something is wrong with me (with my health conditions) I immediately call the reference center. I try to deal with the problem promptly, without waiting for worsening'* (P3). Besides, participants reported that they were trying to *'do the best to feel good'* (P8), following a healthy lifestyle and avoiding situation which could threaten their health, such as potential contacts with the virus.

Recognizing the rapid growth of the pandemic, participants realized they had to cope with the situation by adapting their life to the circumstances: *'I understand I have to adapt my life to what is happening, and I am trying to do my best'* (P2). Therefore, acceptance and adaptation were effective coping strategies that enabled patients to deal with the situation's challenges, and participants showed a peculiar attitude to accept the circumstances that they could not change. Nonetheless, some participants reported that accepting limitations caused by the outbreak was relatively easy because they were used to accept limits dictated by their health conditions, as the pandemic did not excessively change their life: *'Only a few things changed (because of the outbreak), but I am trying to adapt to the situation'* (P2).

In order to facilitate acceptance and the adaptation process, participants resorted to a positive attitude. Optimism and positive thinking allowed them to cope with the situation, so they tried to redirect thoughts towards the positive aspects of the experience: *'The positive aspect is that now if you call someone by phone, s/he will certainly answer because everybody is at home. Before (the outbreak), maybe a person could be busy, while now everyone is available'* (P1). Avoiding thinking about what was happening and diverting attention to something else

was another strategy that participants used for maintaining a positive attitude: 'You set up future goals, for not thinking about the present. For instance, I'd like to go to the mountain, so I'm planning a hike' (P3). Participants believed that divert thoughts towards positive things and 'not thinking about the situation' was 'the right medicine to pass the time and get out of boredom' (P8).

Finally, seeking support from families and healthcare providers was crucial for participants to maintain stable their health status and pursue their goals. On the one hand, professionals' aid was essential, as allowed them to receive home assistance without going to the hospital (for instance, for medications or other minor health issues). On the other hand, receiving support from the family conveyed to participants a feeling of 'safety and reassurance' (P3) that helped them deal with the uncertainty and worries related to the pandemic.

Discussion

To the best of our knowledge, this is the first study aimed at exploring the lived experience of patients with LVAD during the COVID-19 pandemic, using the IPA methodology.⁹ The findings provide the first contribution for understanding the unknown challenges faced by LVAD patients during the pandemic, focusing closely on the impact on people living with a specific chronic heart condition recognized as a very high-risk population vulnerable to a severe illness from COVID-19 infection and then susceptible to major restrictions.¹⁸ Individuals with LVAD have distinctive characteristics compared to other populations of chronic patients,¹⁹ and they are facing a demanding experience that requires a deep understanding of their needs and attitudes. This may help healthcare providers selectively and effectively address patients' needs, activating specific healthcare pathways.¹⁸

Two main themes emerged from the investigation: 'Worsening of psychological distress' and 'Moving forward'. The COVID-19 brought several challenges to patients with chronic conditions, such as patients with LVADs.²⁰ Indeed, the start of the pandemic caused an important change in the daily life of LVAD patients, because they are a high-risk population vulnerable to a severe illness from COVID-19 infection. Accordingly, the re-adaptations of daily life to recommendations to contain the pandemic led patients with LVADs to reveal new and specific healthcare needs, and, consequently, implement positive coping strategies to deal with feelings arising from their health condition awareness.

The COVID-19 pandemic caused a psychological burden on people worldwide,^{21,22} including fear, anxiety, and depressive symptoms, especially in patients with chronic conditions.²³ In our study, patients with LVAD experienced uncertainty and worries as the COVID-19 circumstances threatened their health condition. The LVAD implantation requires a complex process of adaptation, with many daily changes and challenges⁴⁻⁶ often causing distress in patients, leading to psychological issues that can persist throughout time.⁷ Additionally, our results discovered that this LVAD patients' negative mood was amplified during the pandemic.^{6,7} Psychosocial distress refers to the patients' awareness of their frailty and fear of complications related to the device or associated with the risk of COVID-19 infection.

In this regard, a recent study by Bakioğlu et al. (2020) showed that high levels of fear of COVID-19 infection increase depression,

anxiety, and stress. The severity of fear contributes significantly to increased intolerance of uncertainty, depression, anxiety, and stress.²⁴ However, the lived experiences emerged by our interviews do not specify feelings of anxiety and depression, underlining the necessity of further and deepen investigations to define the level of severity of feelings and mood in LVAD patients during the COVID-19 pandemic. So, to date we know that the pandemic impacted the mental illness in LVAD patients, but the psychological scars left behind by COVID-19 will require careful attention because they will determine the future lived experiences of LVAD patients. Knowing the implications beyond COVID-19 in LVAD patients is fundamental to really and deeply understand their feelings and moods, in order to provide tailored support in the care delivery.

Before the start of the pandemic, LVAD patients used to undergo frequent checks and visit with healthcare providers. After the COVID-19 beginning, a lot of checks and visits were suspended in order to guarantee the application of government regulations, and only urgent activities were carried on. These facts had important consequences on the lived experience of LVAD patients, for whom the difficulties in reaching the referral centre pointed out in our interviews increased uncertainty and worries. Our participants expressed trust in the reference centre, recognizing its specific competencies, and expressed a great need to reach it easily, in terms of distance and access to care. The importance of access to specialized care has been recently highlighted²⁵ as a requirement to ensure efficient patient flow across the primary-specialty care²⁶ and a determinant of positive patients' health outcomes, experiences, and satisfaction.²⁷ However, fear and anxiety symptoms may be a normal and functional response during a crisis as relevant as the COVID-19 pandemic, representing stronger predictors of behavioural changes.²⁸

However, different strategies were adopted by LVADs patients to overcome challenges driven by the COVID-19 pandemic. A process of health engagement, acceptance of circumstances, and adoption of positive attitudes were implemented as strategies to deal with the current situation. Health engagement also included self-care interventions, which played a pivotal role during the COVID-19 pandemic to prevent the disease and promote health.⁶ During the acceptance process,⁵ healthcare providers played a crucial role in assessing our patients' emotional state and coping mechanisms during each phase of the adaptation process, requiring a psychological assessment for patients presenting adjustment disorder symptoms.²⁹ Living with an LVAD has significant psychosocial implications, and high social support seems to play a crucial role in moderating the relationship between perceived stress and quality of life in this population. For this reason, authors recently underline the need for a comprehensive plan to address psychosocial factors in these patients.³⁰

The coping strategies applied by participants to face the changes and challenges of the pandemic are recognized as one of the major resources used by LVAD patients. Indeed, Theme 2 is founded on this aspect. We think that it is a peculiarity experienced by people when facing a difficulty. Especially people who usually are in a critical or vulnerable situation can be able to find in themselves the energies and resources to face changes and difficulties. Based on this evidence, it is necessary that healthcare providers not only should be aware of patients' resources, but this (such as the patients coping strategies) should become the starting point for the delivery of care. Our results,

highlighting the coping strategies used by the participants, point out that it is time to bet on people's personal resources and support them through health promotion interventions.

A more in-depth analysis of the findings in relation to previous research on the lived experience of people with LVADs revealed that coping mechanisms to restrictions, including the complexities of care and changes in lifestyle (i.e. alteration in body image, managing device's batteries, bathing and swimming limitations, driving restrictions, and effects on intimacy), represent skills previously acquired by patients after the device placement.⁵ In fact, the implantation of an LVAD significantly affects every aspect of people's lives and demands adjustments to reach new normality.⁶ All these factors contributed to enhancing patients' ability to face COVID-19 challenges.

This study presents several limitations, mostly related to the sample composition. First, despite the efforts made to recruit a homogenous sample, participants came from different Italian regions with different COVID-19 patients' rates, which could lead to differences in participants' lived experiences. Second, this study is limited to investigate the experiences of male patients. While this prevents a broader knowledge of the phenomenon, it deeply provides insight into a specific population cluster. Third, even if all the participants had advanced Heart Failure, they were classified as NYHA Class II and III, while patients with more severe limitations (those in NYHA Class IV) might have different needs. Finally, although our results did not entirely fill the knowledge gap on the lived experience of LVAD patients during the pandemic, they produced an initial in-depth knowledge of this phenomenon, representing the first attempt to incentive research on the peculiarity and needs of this population.

Conclusion

This study shines a light on the lived experience of people with LVAD during a pandemic, providing a deep and initial understanding of the lived experience in terms of challenges in daily life and care burden. Specifically, the application of the IPA methodology allowed for deeply exploring the live experiences of LVAD patients, and the new information that emerged from our results represent a first and initial knowledge of the phenomenon, to date little investigated, raising new research questions, and highlighting the need for further empirical evidence. Indeed, our results highlight additional negative and positive aspects experienced by LVAD patients (i.e. *Worsening of psychological distress*): on the one side, a sense of constant worries and solitude leading to distress; on the other hand, the ability to perform behaviours to 'Moving forward', allowing them to face the situation.

These results are relevant for both clinical practitioners and researchers. As for clinical professionals, understanding the vulnerability, challenges, and needs of LVAD patients during a pandemic is relevant for better responding to them. Indeed, the COVID-19 pandemic has completely changed the lives of all of us, remodelling the daily activities and redesigning the priorities of life. However, these changes are more significant for some categories of people worldwide, such as the patients with a chronic illness (i.e. LVAD patients) because of their extreme vulnerability. Accordingly, these aspects must be the start point to tailored care delivery, from which healthcare providers can realize interventions and supports. For instance, the worsening of psychological distress expressed by our participants

highlights a need for psychological support, which could be provided also during a pandemic using phone calls or video calls; similarly, telemedicine services could be useful for constantly monitoring these patients' clinical conditions and providing professional guidance in self-care and the management of the disease, without exposing the patient to the hospital environment and the risk to contract the virus. Furthermore, results coming from our study provide a first understand of the lived experience of LVAD patients, and add a further piece of knowledge on a very vast and still little explored phenomenon. Future research is needed for exploring the psychological scars left behind by COVID-19, its impact on LVAD patients' outcomes, and the feasibility and effectiveness of new targeted interventions. Also, future research should be focused on the lived experiences of additional population clusters with LVAD, such as different NYHA classes or sex-related differences,^{31,32} to target specific needs, bring to light differences, and reach a full understanding of the phenomenon. Accordingly, recent evidences³³ seem to underline sex-related differences in LVAD patients' clinical outcomes, but it is needed to achieve further evidences on this aspect.

Funding

This research was partially supported by 'Ricerca Corrente' funding from the Italian Ministry of Health to IRCCS Policlinico San Donato.

Conflict of interest: none declared.

Data availability

Derived data supporting the findings of this study are available from the corresponding author (F.D.) on request.

References

- Willan J, King AJ, Jeffery K, Bienz N. Challenges for NHS hospitals during COVID-19 epidemic. *BMJ* 2020;**368**:m1117.
- Salzano A, D'Assante R, Stagnaro FM, Valente V, Crisci G, Giardino F, Arcopinto M, Bossone E, Marra AM, Cittadini A. Heart failure management during the COVID-19 outbreak in Italy: a telemedicine experience from a heart failure university tertiary referral centre. *Eur J Heart Fail* 2020;**22**:1048–1050.
- Mariani S, Hanke JS, Dogan G, Schmitto JD. Out of hospital management of LVAD patients during COVID-19 outbreak. *Artif Organs* 2020;**44**:873–876.
- Wilson SR, Givertz MM, Stewart GC, Mudge GH. Ventricular assist devices the challenges of outpatient management. *J Am Coll Cardiol* 2009;**54**:1647–1659.
- Abshire M, Prichard R, Cajita M, Digiacomio M, Himmelfarb CD. Adaptation and coping in patients living with an LVAD: a metasynthesis. *Hear Lung J Acute Crit Care* 2016;**45**:397–405.
- Luciani M, Trenta AM, Jack SM, Moro M, Patella S, Di Mauro S, Ausili D. Adults living with a retro-auricular left ventricular assist device as destination therapy. *J Cardiovasc Nurs* 2020;**35**:E62–E69.
- Modica M, Ferratini M, Torri A, Oliva F, Martinelli L, De Maria R. Quality of life and emotional distress early after left ventricular assist device implant: a mixed-method study. *Artif Organs* 2015;**39**:220–227.
- Sayer G, Horn EM, Farr MA, Axsom K, Kleet A, Gjerde C, Latif F, Sobol I, Kelley N, Lancet E, Halik C, Takeda K, Naka Y, Yuzefpolskaya M, Kumaraiah D, Colombo PC. Transition of a large tertiary heart failure program in response to the COVID-19 pandemic: changes that will endure. *Circ Hear Fail* 2020;**13**:e007516.
- Smith JA, Flower P, Larkin M. Interpretative phenomenological analysis: theory, method and research. *Qual Res Psychol* 2009;**6**:346–347.
- Flocco SF, Caruso R, Barello S, Nania T, Simeone S, Dellafiore F. Exploring the lived experiences of pregnancy and early motherhood in Italian women with congenital heart disease: an interpretative phenomenological analysis. *BMJ Open* 2020;**10**:e034588.

11. Albanesi B, Nania T, Barello S, Villa G, Rosa D, Caruso R, Udugampolage NS, Casole L, Dellafiore F. Lived experience of patients in ICU after cardiac surgery: a phenomenological study. *Nurs Crit Care* 2020.
12. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med* 2014;**89**:1245–1251.
13. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, Burroughs H, Jinks C. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant* 2018;**52**:1893–1907.
14. Crowe M, Inder M, Porter R. Conducting qualitative research in mental health: thematic and content analyses. *Aust N Z J Psychiatry* 2015;**49**:616–623.
15. Tufford L, Newman P. Bracketing in qualitative research. *Qual Soc Work* 2012;**11**:80–96.
16. Sandelowski M. Focus on research methods-whatever happened to qualitative description? *Res Nurs Heal* 2000;**23**:334–340.
17. van Nes F, Abma T, Jonsson H, Deeg D. Language differences in qualitative research: is meaning lost in translation? *Eur J Ageing* 2010;**7**:313–316.
18. Xanthopoulos A, Triposkiadis F, Starling RC. Care for patients with ventricular assist devices and suspected COVID-19 infection. *Eur J Heart Fail* 2020;**22**:937–940.
19. Ben Gal T, Ben Avraham B, Abu-Hazira M, Frigerio M, Crespo-Leiro MG, Oppelaar AM, Kato NP, Stromberg A, Jaarsma T. The consequences of the COVID-19 pandemic for self-care in patients supported with a left ventricular assist device. *Eur J Heart Fail* 2020;**22**:933–936.
20. DeFilippis EM, Reza N, Donald E, Givertz MM, Lindenfeld JA, Jessup M. Considerations for heart failure care during the COVID-19 pandemic. *JACC Hear Fail* 2020;**8**:681–691.
21. Barello S, Nania T, Dellafiore F, Graffigna G, Caruso R. "Vaccine hesitancy" among university students in Italy during the COVID-19 pandemic. *Eur J Epidemiol* 2020;**35**:781–783.
22. Nania T, Dellafiore F, Caruso R, Barello S. Risk and protective factors for psychological distress among Italian university students during the COVID-19 pandemic: the beneficial role of health engagement. *Int J Soc Psychiatry* 2021;**67**:102–103.
23. Musche V, Bäuerle A, Steinbach J, Schweda A, Hetkamp M, Weismüller B. COVID-19-related fear and health-related safety behavior in oncological patients. *Front Psychol* 2020;**11**:1984.
24. Bakioglu F, Korkmaz O, Ercan H. Fear of COVID-19 and positivity: mediating role of intolerance of uncertainty, depression, anxiety, and stress. *Int J Ment Health Addict* 2020;1–14.
25. Greenwood-Lee J, Jewett L, Woodhouse L, Marshall DA. A categorisation of problems and solutions to improve patient referrals from primary to specialty care. *BMC Health Serv Res* 2018;**18**:986.
26. Blundell N, Clarke A, Mays N. Interpretations of referral appropriateness by senior health managers in five PCT areas in England: a qualitative investigation. *Qual Saf Heal Care* 2010;**19**:182–186.
27. Sanders GD, Bayoumi AM, Sundaram V, Bilir SP, Neukermans CP, Rydzak CE, Douglass LR, Lazzeroni LC, Holodniy M, Owens DK. Closing the quality gap: a critical analysis of quality improvement strategies (vol. 3: hypertension care). *N Engl J Med* 2005;**352**:570–585.
28. Harper CA, Satchell LP, Fido D, Latzman RD. Functional fear predicts public health compliance in the COVID-19 pandemic. *Int J Ment Health Addict* 2020; 1–14.
29. Casida JM, Marcuccilli L, Peters RM, Wright S. Lifestyle adjustments of adults with long-term implantable left ventricular assist devices: a phenomenologic inquiry. *Hear Lung J Acute Crit Care* 2011;**40**:511–520.
30. Abshire M, Russell SD, Davidson PM, Budhathoki C, Han H-R, Grady KL, Desai S, Dennison Himmelfarb C. Social support moderates the relationship between perceived stress and quality of life in patients with a left ventricular assist device. *J Cardiovasc Nurs* 2018;**33**:E1–E9.
31. Dellafiore F, Arrigoni C, Pittella F, Conte G, Magon A, Caruso R. Paradox of self-care gender differences among Italian patients with chronic heart failure: findings from a real-world cross-sectional study. *BMJ Open* 2018;**8**:e021966.
32. Dellafiore F, Conte G, Baroni I, Magon A, Pittella F, Casole L, Caruso R. Gender differences in heart failure self-care behaviors: do we know enough? *Minerva Med* 2018;**109**:401–403.
33. Mariani S, Li T, Bounader K, Boethig D, Schöde A, Hanke JS, Michaelis J, Napp LC, Berliner D, Dogan G, Lorusso R, Haverich A, Schmitto JD. Sex differences in outcomes following less-invasive left ventricular assist device implantation. *Ann Cardiothorac Surg* 2021;**10**:255–267.