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DISSERTATION

Understanding the quality of life of patients living with a Left Ventricular Assist Device: A qualitative approach
/
Die Lebensqualitität von Patienten verstehen, denen ein Herzunterstützungssystem (LVAD) implantiert wurde: Ein qualitativer Ansatz

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List of abbreviations

KCCQ: Kansas City Cardiomyopathy Questionnaire

LVAD: Left ventricular assist device

MLHFQ: Minnesota Living with Heart Failure Questionnaire

QoL: Quality of life

QoLVAD: QoL with a Ventricular Assist Device

Abstract

In addition to saving a life, a paramount aim of left ventricular assist device (LVAD) implantation is to enhance the patient's quality of life (QoL). While current quantitative methods do assess QoL using questionnaires in these patients, they lack the ability to understand the deeper and subjective experiences of this cohort, missing many nuanced factors that may affect well-being. Our study aims to fill this gap using a qualitative, interview based methodology. In order to do this, we used the Colaizzi phenomenological approach, with purposive sampling of willing patients that have lived with an LVAD for at least 6 months. Twenty-one were interviewed in total. Many factors were shown to have an influence on the patients QoL, including their current health condition, social interactions, sexual activity, and psychological problems. We have shown that LVAD patients have unique concerns, and their issues highlighted in our study require more attention, counselling before and after implantation, and ongoing care after leaving the hospital.

Zusammenfassung

Neben der Rettung des Lebens eines Patienten ist die Verbesserung der Lebensqualität (QoL) ein wichtiges Ziel der Implantation eines linksventrikulären Unterstützungssystems (LVAD). Die derzeitigen quantitativen Methoden verwenden Fragebögen um die Lebensqualität dieser Patient*innen zu bewerten, sind aber nicht in der Lage, die tieferen und subjektiven Erfahrungen dieser Patient*innen zu verstehen, so dass viele nuancierte Faktoren, die das Wohlbefinden beeinflussen können, nicht berücksichtigt werden. Unsere Studie zielt darauf ab, diese Lücke durch eine qualitative, interviewbasierte Methode zu schließen. Zu diesem Zweck verwendeten wir den phänomenologischen Ansatz von Colaizzi mit einer gezielten Auswahl von Patient*innen, die länger als 6 Monate mit einem LVAD leben. Insgesamt wurden 21 Patient*innen befragt. Es hat sich gezeigt, dass viele Faktoren einen Einfluss auf die Lebensqualität unserer Patient*innen haben, darunter ihr aktueller Gesundheitszustand, soziale Interaktionen, sexuelle Aktivitäten und psychologische Probleme. Wir haben gezeigt, dass LVAD-Patient*innen ganz besondere Sorgen haben und dass ihre Probleme, die in unserer Studie hervorgehoben wurden, mehr Aufmerksamkeit, Beratung vor und nach der Implantation sowie eine kontinuierliche Betreuung nach dem Verlassen des Krankenhauses erfordern.

1. Introduction

A left ventricular assist device (LVAD) is a mechanical pump that supports the function of a failing left ventricle and has an inner and outer component (1-3). It sits on or adjacent to the heart's cleared out ventricle and is connected to a tube that leads blood to the aorta, although some models sit outside the body and are connected to the heart via tubes (paracorporeal LVADs) (4). A driveline cable extends out through the skin and connects to a controller worn outside the body. It is powered by batteries or through mains power (5). **(Figure 1)** LVADs continue to be applied successfully in cases involving heart failure and the most common devices offer continuous flow, offering patients an option as a bridge to transplantation or as long term therapy for those who do not qualify for transplantation (6). In this case, they represent a permanent solution for supporting the heart's pumping function (7). Additionally, they can be used as a bridge to recovery solution, offering temporary support to allow the heart to heal from acute myocardial injury or a reversible condition such as myocarditis or post-cardiotomy shock (8) Finally, in some complex cases, LVADs are used as a "bridge to decision", providing temporary support while further evaluation and assessment take place to determine the most appropriate treatment (7) The latest generation offers excellent results in functional status and outcome, but complications such as thrombo-embolic events, right heart failure, infections, and bleeding can still occur (9). The presence of any foreign device can increase the risk for infection. Such infections can be local, such as at the driveline or exit locations, or systemic, such as bloodstream infections (4). Blood clotting may form within the LVAD or associated components, leading to possible stroke or device malfunction. This is prevented using anticoagulation therapy, but this can also cause unwanted bleeding as a side effect (6, 7) Other complications may include device malfunction, such as issues with the pump, driveline or power supply (this requires prompt intervention), and hemolysis, where the mechanical forces caused by the device lead to red blood cell damage, potentially resulting in anemia and the need for blood transfusions (6).

However, for end stage heart failure patients, LVADs continue to remain one of the only viable options for therapy, and patients receiving them have gradually increased globally (10-12). Studies have shown that LVAD therapy improves survival rates and enhances quality of life (13). LVAD support has been associated with a reverse remodeling of the heart, including and reduction in ventricular size and improvement in cardiac function (14).

Furthermore, they provide hemodynamic support by increasing cardiac output and reducing ventricular workload, improving end organ perfusion (15). As the heart improves its function, end-organs also benefit, and the patients with advanced heart failure also show improved renal and hepatic function after implantation(16).

With these benefits in mind, it has been increasing urgent to provide data regarding quality of life for these patients. For our patient cohort, quality of life can be variously influenced by social and economic factors, the severity and development of their condition, and their subjective views of life satisfaction (17). These could be affected by implantation in various ways, which include emotional and cognitive functioning, as well as physical and sexual performance (18). The latter is often caused by the physical limitations of the device, as due to its size and weight, strenuous activities and contact sports are discouraged to avoid dislodgement and damage to the LVAD (4). The device requires a stable power supply for operation, and patients must be able to access a reliable power source and carry backup batteries at all times(19). This also limits the variety of activities they are able to participate in. Living with an LVAD can be emotionally taxing on the patient and caregivers, as adjusting to the device, coping with the lifestyle changes, and managing the psychological impact of a chronic condition can pose various challenges (20). These include lifestyle adjustments resulting from the need for regular medical appointments, monitoring of the device parameters, and adherence to medication regimens(20). Additional problems could be posed by device malfunctions, neurological difficulties, or infections (21). To minimize the risk of infection, patients must follow strict procedures which include regular dressing changes, proper hygiene and adherence to infection control protocols(22).

Figure 1: Continuous Flow left ventricular assist device. Reproduced with permission of Medtronic, Inc (23).

Quantitative studies such as the Kansas City Cardiomyopathy Questionnaire (KCCQ), EQ-5D-5L-EQ-5D, Minnesota Living with Heart Failure Questionnaire (MLHFQ) and the QoL with a Ventricular Assist Device (QoLVAD) Questionnaire are the current tools used to measure quality of life in LVAD patients (18, 21, 24, 25). These surveys can gather a significant amount of information from a large number of participants relatively quickly but tend to summarise the patients' subjective experiences without much differentiation (26). Additionally, several questionnaires are only applicable to general patients with heart failure and not those implanted with an LVAD, offering no applicability to our patients. The purpose of this study is to understand the quality of life of patients implanted with an LVAD. We hope to add more detailed data on subjective life experiences in patients (7, 27, 28) with LVAD that these questionnaires were not capable of elucidating, and as a result of this, hope that this data can be used to improve patient care and support.

2. Methods

This section presents the methodological approach that will be undertaken, as informed by the gaps identified in the literature. The chapter discusses the philosophical stance, research strategy and research method for data collection.

2.1 Research Philosophy

This study focused on uncovering, understanding and providing description of the lived experience of having an LVAD. In order to ensure the quality of our study, we evaluated different philosophies and ways of approaching a qualitative study. The method selected was phenomenology, which offers a way to identify patterns, connections and themes of a person's experience. This is a method of inquiry that involves engagement with participants and their interpretations of their lived experience (29). It allows researchers the opportunity to define their position within the research and understand the experience at a deeper level than other approaches to research. It is not only a philosophy behind the research but also a method of inquiry (30). This method has a number of advantages including it is relatively quick, uncomplicated and can be used when it is difficult to access smaller numbers of people.

2.2 Research Strategy

The structure of the study followed a qualitative method of data collection using semi-structured interviews that asked the participants regarding their experiences with an LVAD. These questions were created by defining the research question and also assessing other scientific literature on lived experience. An interview guide (**Table 1**) including the questions were then assessed by a sociologist and tested on two patients that were not within the cohort of the study. The questions included following themes: Life prior to diagnosis and implantation, life changes after diagnosis and implantation, daily routines of the patients, their subjective evaluation of how difficult their life had become, the role of their family and friends, their relationship with the medical staff, their support structures and whether they felt they were receiving enough support, whether they received professional help at home, how they felt about the doctor patient relationship, whether the implant had limited their lives, and any other statements they wished to make.

Table 1: Interview guide, own elaboration

1. Can you please tell me about your life before the diagnosis was made? How did you know you had a problem? What did you do, how did you feel?
2. How did your life change after the diagnosis? Please can you tell me about your experience since implantation? What does it mean for you to have this disease?
3. Can you please tell me about your life after the implantation. Have you felt an improvement in your quality of life? Can you give some examples?
4. Do you also have the feeling that something in your life is more difficult now, or is there something that you do not like after implantation? Can you give some examples?
5. Could you please tell me about your daily routine, what does a normal day in your life look like?
6. How did it change before/after the implantation?
7. What about your family and friends, do they notice some improvements? Did they tell you their impressions before and after the implantation?
8. Please describe the relationship you have with the medical staff.
9. Do you get enough support? Do you feel well treated? Did you get answers to your questions?
10. Do you have professional help at home?
11. Based on your experience, is there anything you think can be improved regarding the doctor-patient relationship?
12. Is there anything you would like to do but cannot do because of the implant?
13. Is there anything else you would like to tell me about your before/after implant experience?

2.3 Participants

This study utilised a non-probability style of sampling; Purposeful sampling. Purposeful sampling is a technique commonly used in qualitative research to identify and select information-rich cases in order to make the best use of limited resources (31, 32). With this method of sampling, data is collected from people that are conveniently accessed and, in this study, participants had to be recruited with specific inclusion and exclusion criteria (discussed below in further detail).

Our study included a total of 30 participants at the German Heart Center in Berlin, which treats acquired heart problems as well as congenital defects for all ages and severities. The center performs over 100 LVAD implantations every year. The criteria we used for inclusion were: Having lived with the implant for more than 6 months, being in good mental and physical health, and being over 18 years old. Patients presenting for outpatient follow-up and meeting our criteria were approached for the study. This time frame was chosen so they could gather more experience with the device, as patients with the implant are usually very sick and have end stage heart failure, requiring several weeks of recuperation as well as time to adjust to daily life with mechanical circulatory support. We did not select patients who did not visit the hospital during the period which we recruited. We continued asking patients questions until we were satisfied that there was no more additional data we could receive from them, that is data saturation. Data saturation refers to the point at which no new information is being discovered during the interviews. Six patients chose not to participate, and three did not survive to be interviewed. Thus, of our selection, 21 participated in the end. They were additionally asked for their full consent, in writing, and were guaranteed that they would remain anonymous.

2.4 Data Collection

The interviews took place between December of 2019 and February of 2020, and the person leading the interviews was a medical doctor that received training in performing such interviews for the purpose of extracting qualitative data. Moreover, a sociologist reviewed the selection of the topics and confirmed that they would be suitable for a qualitative study. The interviews were conducted in a quiet hospital room in the German language, and information about the patient, such as marital status, age, sex, work and residence were assembled and then confirmed by the patients. The questions were established by a group of nurses and doctors who already had experience regarding patient care with those implanted with an LVAD. During the interviews, the patients were asked to give a description of their feelings and what they meant, in a narrative fashion. The interviews lasted up to an hour, and the participants were given the freedom to say whatever they were feeling at the moment. Follow up questions were sometimes asked, if necessary, to clarify intent. The interviewer adopted an empathetic stance towards the

patients in order to encourage them to open up as much as possible. As the researcher, I provided very little input regarding my opinions and personal biases and listened in an interested, nonjudgmental and responsive manner. Interviewing continued until the information contained a substantial amount regarding the question at hand in order for the understanding to be clear. In the end, patients were given a chance to add anything additional to the conversation that the interviewer may have missed.

The primary source of data collection was this interview which was then transcribed. All of the interviews were recorded with audio, with additional notes being taken to record non-verbal communication and situational factors. The data gathered also included a section that acknowledged any personal biases that could potentially influence data collection or analysis as they were recognized.

The data was then processed with Colaizzi phenomenological analyses, revealing interconnected relationships and themes. This included a seven step approach to qualitative research that intended to keep the researcher near to the data. Firstly, all of the interviews were read and marked-up with comments to identify themes. This also offered an opportunity for me to acquire a feeling for and an understanding of them. If ideas or statements were significant, they were extracted. Repetitions were then found were it was applicable, and finally, categories were created for the various themes. This included relevant statements for themes in each transcript. Understanding the different perspectives and interpretations of the participants was important. These re-organized transcripts were then returned to the patients to see how they compared with their lived experiences. Many steps to ensure the accuracy and integrity of the results were taken. Trustworthiness can be described as a way of persuading the audience that the findings of the study are worth paying attention to and worth taking account (31). To ensure trustworthiness, the transcripts were read collectively by the study team and the sociologist coded them separately as an additional control. To further ensure lack of bias, we identified personal and team values and assumptions at the outset and acknowledged any that were found to exist along with the log of personal biases identified during the interviews. This step helps to further establish trustworthiness as it confirms whether or not the interpretations accurately reflect the participants' lived experience. The final goal was to withhold any existing notions or biases about our patients lived experience.

I have attempted to provide clear and detailed descriptions of all of the information surrounding the process of the research in order for the information in the study to be transferred to another setting, context or place in time.

2.5 Ethics

This prospective study was reviewed and approved by the ethics commission of Charité Medical University Berlin in December 2019 (EA2/144/19). All participants were duly informed of the objectives of the study and gave explicit informed consent prior to participation.

3. Results

The following section discusses the demographics of the participants and the themes that emerged from the study upon analysis and interpretation. The main themes that emerged included; improvements/setbacks, burdens of the device, limitations in physical activity, sexual activity, social interactions, psychological and emotional problems, support and optimistic feelings.

3.1 Patient Characteristics

The patients were between 37 and 78 years old and had a median age of 61 years. The time between implantation and our study had a median of 26 months (IQR 38). All of the participants were part of the labor market before they received their LVADs. We found a number of themes that could be extracted from the interviews.

3.2 Themes

1. Improvements and setbacks

The conditions of the patients varied. A majority of the patients said that their symptoms had improved, with a 60 year old man reporting that he could now climb the stairs, whereas before he could not. Another woman reported that she was able to work in her garden again after being unable to do so before receiving the implant. Another woman said that her breathing had improved. Among the patients who reported that their condition had deteriorated, complaints involved increased breathing difficulties and swollen legs that had not improved after the implant.

2. Device burdens

Many participants had things to say about the device. All of them complained that it was too heavy and caused them additional pain in the back, waist, and shoulder. Since the patients were lying down during the period of recuperation, many did not feel the weight of the machine until they had returned to the activity in their day to day lives while standing up or moving. Another issue the participants struggled with was the battery life of the implant. All of the patients received an implant with a runtime of

around 10 hours on one charge. This posed some problems for the patients, as they reported forgetting to pack an additional battery during an outing and needing to cut it short or having to charge the batteries too frequently. This often frustrated them and made them feel dependent on factors outside of their control. Some also complained that the cable of the implant was too short and how they were attached to their body. Most of these patients wished that the cable was longer.

3. Limitations in physical ability

Nineteen of our 21 patients reported needing to reduce their physical activity after having received the implant. Previously, they had often participated in running, swimming or biking, and a majority of them could not perform these activities at all after implantation. A 46 year old man was unhappy that he had to give up a body-building hobby, as he was unable to train at the gym, while a 37 year old man similarly reported being unable to jog or cycle with his wife. Sleeping also emerged as an issue for several participants, with some complaining of no longer being able to sleep on their side, such as a 54 year old woman who loved sleeping on her left side and was prevented from doing so after receiving the implant.

A number of participants struggled with being able to travel, with all except for two patients reporting difficulty in this area. Travel was often accompanied with increasing limitation and complication, as the batteries and accessories needed to be packed, and any risk of the device malfunctioning while away and without emergency help could pose life-threatening to the patient. This was particularly important for a 61 year old man who previously traveled to Asia and Thailand, but presently could not go such a long distance due to these complications. Another 57 year old man reported that checking in at airports was problematic due to airline personnel being unfamiliar with the device. He was often subjected to interrogation, which humiliated and discouraged him from traveling longer distances.

Employment was an important topic during the interviews as well. None of the patients were employed after receiving implant, even though all of them were beforehand. A 61 year old man, who previously worked as a banker, complained that losing his job had a large impact on this quality of life, as he had loved his job and was forced to give it up. This was difficult for him to come to terms with. Most of the participants were forced into early retirement as a result of receiving the implant, with a 57 year

old woman reporting that she could no longer shop as she usually did due to her severely limited income. This lack of money was an issue that reared its head with several other patients, and they reported that this had a big impact on their quality of life. However, one participant did report that due to some clever financial arrangements he had made regarding his business, he was very satisfied in this area.

4. Sexual activity

Moreover, the implant also had a big impact on the sexual lives of our participants. All but one of them were sexually active before the operation, but all of them had their sex lives negatively impacted or even eliminated through receiving the implant. In our study, the women were not as disturbed by this compared to the men, with one 55 year old woman reporting that although her sex life was not the same, it didn't bother her, and it would even not bother her if she had no sex life at all. A 54 year old woman had more anxiety regarding the machine and felt that resuming her sex life was not worth the risk. Often times the reason for the machine negatively impacting our participants sex life was one of reduced libido or issues with body image. These were more often reported by the men. Three men said they were ashamed with the bodies and did not believe their partners would find them attractive, and all of them, with the exception of one woman, reported decreased libido. A few participants mentioned the complexity of the device, the position of the driveline or fear that it would disconnect during sexual activity. This caused them anxiety.

5. Social interactions

The patient's social lives were heavily impacted by implantation. Seventeen out of the 21 reported a decreased level of social interaction with family and friends. These were mostly the younger participants. The reasons varied between lack of money for socializing, no longer living a care-free lifestyle as they used to have, or no longer accommodating as many visitors as before. These issues were not as severe with the older patients.

6. Emotional and psychological problems

Among our cohort, many also reported emotional and psychological difficulties. Eight reported feeling stressed, while six felt depressed. A 46 year old man felt the machine had degraded him compared to other people. A particularly unique story was offered by a 37 year old women, who reported regretting having a child, because it led her to suffer postpartum cardiomyopathy. This then resulted, in her view, in the loss of her job and husband afterward. 15 of the 21 participants reported feeling a sense of loss, saying that they could not participate in the same activities that they used to do, for example with their spouses, and a 61 year old man felt a loss of his own identity, saying that he was not the same person that he used to be after the implant. Sometimes, this loss was linked to a feeling of freedom, with a 66 year old man reporting that he needed to give up so many things compared to his previous life, that it felt like being reduced to spare parts, with which without he could not live. Anxiety arose as a common issue among patients reporting emotional difficulties. This revolved around the implant malfunctioning, social anxiety resulting from how they would be perceived by others, or anxiety regarding the future. For one grandfather, his fear of the device not working as intended prevented him from playing with his grandchildren, one of his favorite activities. He reported that it was too great a risk in case they pulled a cable or disconnected the device in some way. Seven patients reported a fear of using public transport, which was often related to the fear of others noticing the device. This was particularly acute in a 60 year old man, who felt that he might be a victim of theft or assault if people misinterpreted the bag containing the device as something valuable or worth stealing. Finally, a fear of what the future would hold played a role in the anxiety of many patients. Some of the patients under 66 years old expressed that they did not know how long they had left to live or how the implant would affect their life expectancy, and that this uncertainty added to their existing anxieties and prevented them from making long-term plans.

7. Support

All of the participants however continued to receive support from friends and family. A majority of them reported having become closer to their family and friends since receiving the implant, and that they also valued them more. A 64 year old man

expressed that his brother and wife had been offering support, while a 70 year old woman said that her daughter had moved to Berlin from Munich to help her. A 61 year old man had mixed feelings, as the amount of bureaucratic paperwork he needed to do as a result of the life changes occurring from implantation had meant he needed a lot of help from his friends. He felt that this was causing him to become a burden to them. This was also felt by a third of the male patients, who reported that they tended to avoid meeting up with family and friends because they felt they had become a burden.

8. Optimism

Finally, our participants also expressed some positivity in the study. Two thirds of all of the patients reported an optimistic attitude on life as a result of the implant. A 37 year old man said that he was sure his condition would improve, while a 57 year old man said he was very optimistic about the future, partly because he expected the quality and performance of the implant to improve over time. Most of the patients also voiced happiness that the device had saved their lives and given them a second chance and hoped that they could use the extra time they were given to improve themselves or live a healthier lifestyle.

3.3 Summary

The results presented in this chapter highlight the themes that emerged from the analysis and interpretation of the semi-structured interviews. Participants identified a number of themes related to living with a LVAD including improvements/setbacks, burden of the device, limitations in physical activity, social interactions, sexual activity, emotional and psychological problems, support and optimism.

4. Discussion

4.1 Short summary of results

Between men and women, six of the nine categories had equal importance, whereas men reported more sexual and physical problems, problems with fear, and problems with social interaction. Women reported having sleep issues more often than men. The older patients did not have as many concerns with the themes of social interaction and fear. As for complaints regarding the device itself, our study found similar concerns to a study conducted by Adams and Wrightson (25). LVADs have become smaller in the past few years (2, 33) but an even smaller and lighter device would clearly benefit these patients. Complaints for example, regarding the length of the cable could be easily solved, nonetheless.

The literature already includes examples of LVAD leading to the inability to work and early retirement (34), however this is not usually included in quantitative surveys. Our study revealed this as a major issue for nearly all of the participants, which resulted in not only financial problems, but also psychological ones. Increased patient support that could provide new avenues of work could help alleviate these burdens. Our finding agrees with studies (35) that show that their closeness to their partners had increased after implantation. This often results from increased dependency on their loved ones. Questionnaires do not address sexual function, and this was an important part of our study. As all of our patients were active sexually before receiving the implant, and afterwards reported significant hindrance or cessation, it was critical for us to capture this change and see how it affected their quality of life. Our patients reported that these problems were often caused by anxiety connected with the device malfunctioning, or issues they had with their body image. Sexuality is a crucial part of intimacy and important for quality of life (35), so these concerns could be alleviated with intervention in the form of psychotherapy or partner therapy.

4.2 Interpretation of results

The discoveries we made in our study overlapped broadly with similar studies on patients that received LVAD implantation. Existing studies already show that there is an immense need for patients with advanced heart failure to receive better care (36), and these

patients suffer from a variety of physical and psychological issues from less than optimal care. These patients require specialized treatment and models need to be developed in healthcare settings to better serve them. We also came to this conclusion in our study. Existing quantitative studies, such as Gustafsson (13), show that outcomes related to survival and quality of life (such as a 6-min walk test distance) all improved after implantation, although adverse events continue to be common. Studies using questionnaires, such as Grady (37), also capture an increase in quality of life for LVAD patients independent of age or gender, although younger patients and women in the study reported more problems regarding pain and anxiety/depression compared to other cohorts. We were not able to mirror these results exactly, but we did find some differences between genders relating to sexual and social problems, so we believe such differences may exist to a degree. A systematic review by Friedman (38) came to the conclusion that patients did not receive enough information at the consent stage, resulting in poorer outcomes. Although the primary motivation of patients was to avoid death and reduce their symptoms, Friedman found that patients often had the belief that the implant would reverse or fix their illness, and thus were often disappointed at results, setbacks, or limitations of the device. We also found this sentiment among many patients we interviewed. He concludes that informed decision making during the consent process needed to be improved, and we concur with this sentiment, as some of the patients in our study expressed disappointment with the discrepancy between what they were promised and how their lives developed after the implant.

4.3 The current state of research

According to quantitative questionnaires, patients often experience an improvement in quality of life, especially exercise capacity. However, as mentioned before, these survey often do not capture important elements of a patient’s subjective life experience. Individual coping, including their perceptions and response to receiving the implant often go unmentioned. Our study aimed to fill these gaps. However, some past studies share more similarities with ours and were framed in a more qualitative way. Many of those are nevertheless reviews and meta-studies, like those of Friedman (38), and therefore do not bring any new insights. Some studies were more unique, such as Grady (39), which compared outcomes after LVAD implantation to outcomes after heart transplant, finding that the picture was mixed but that in general transplantation resulted in better outcomes.

This was captured using self-reported questionnaires. These studies are important, but lack the qualitative data that we were able to collect using direct interviews.

4.4 Strengths and weaknesses of the study

It should be mentioned that we believe our study contains a number of limitations. As it was a qualitative study conducted at only one hospital, the data would not be able to be projected on a wider population, and we support the continuation of these types of studies at multiple locations with a larger population. Our study was also conducted in a developed country, which may also have differences in culture compared to other countries. We also did not consider or filter for the socio-economic status of our participants. Germany enjoys a highly developed, relatively universal healthcare system, and this could have had an impact on how our patients assessed their subjective quality of life. Patients in our study also needed to have the device for at least 6 months, which could have caused selection bias, because we were unable to capture the quality of life of sicker patients that may have died sooner. Nevertheless, because most LVADs are implanted in wealthy countries, we believe these limitations are still likely to be of value for hospital personnel and clinicians. The number of LVAD patients continues to increase, and it will be valuable for caretakers of these patients to understand how they can increase the quality of life of their patients and to prepare them, physically and psychologically, for what lies ahead. This should include post-operative education and helping them adapt to their daily lives upon leaving the hospital. We have shown that patients also have a desire to improve their relationship with their doctors and nurses, and increased knowledge about these patients' subjective experiences can help these hospital employees increase their empathy and understand of LVAD patients. As LVADs are often used for destination therapy due to a shortage of hearts, doctors and nurses also have the task of preparing the patient for a permanent transition to mechanical heart support and not just as a bridge to transplant. Akhter et al. (31) proved that LVADs do improve cardiomyocyte hypertrophy, myocardial ischemia, and coronary perfusion, making the device also useful as a bridge to recovery. The future implications for having a better understanding of the lived experience of LVAD patients will allow for research developments for the device, better education about life changes and improvements into areas required for support.

4.5 Implications for practice and future research

Medical disorders often connected with LVAD implantation include stroke, infection, bleeding, pump thrombosis, right heart failure, or device malfunction often has a negative impact on quality of life for patients. Patients are well informed beforehand regarding outcomes and complications, but we found that they often had high expectations regarding the outcome of the implant, and that this was confirmed by other studies (40, 41). Medical providers should take a closer look at how they brief patients prior to implantation and if they are providing a realistic picture of what patients should accept in terms of recovery and complications. Families of the patients should also have realistic expectations of how the implantation will change the lives of the patients and be prepared to cope with these changes.

Negative factors for patient prognosis and recovery include depression and anxiety, which worsened heart failure (42, 43) and lead to incompliance and risk of re-admission to the hospital (44). As our study found, these psychological problems were a major issue, which could be alleviated with the proper support systems in place. However, our patients also showed a great deal of optimism and gratitude and were happy to be alive and given a second chance. The existing literature does not capture the social aspect so well, and we showed that social interaction was negatively impacted by upset finances, body image issues, and inability to work. Social media has been shown to have a positive impact of LVAD patients, allowing them to form social connections with other patients (45), as well as providing an avenue for further education, improved decision making and enhanced support, and should be further encouraged.

5. Conclusions

As we have shown, it is important to understand the concerns of patients that have received an LVAD implant. Patients have undergone physical and emotional changes and have the need to support groups and networks to help them transition towards a new life. Each of our patients had their lives saved by the implant, and each of them adjusted to the implant in a way that was personal to them. Previous studies have shown that implantation improved quality of life and our study has added nuance to this by further ascertaining the degree to which these patients' lives have been changed, improved, or hindered.

We have revealed many areas which need further attention and improvement, and hope to help healthcare providers and manufacturers of the device to make changes that could lead to better care for these patients, particularly regarding the mechanics of the device, as well as follow up care. Another future research need is to consider the different approaches to research and include mixed methods and more qualitative research to better understand health related QoL measures. We urge healthcare providers to pay closer attention to these findings to help implement strategies to manage LVAD patient care.

The number of participants is not a limitation to the qualitative work of this study, however a broader reach and understanding of issues surrounding patients from other hospitals and perhaps countries would be important to confirm the generalisability of the findings. As technology continues to evolve, we can assume that more patients will receive a LVAD and that there will also be improvements to the device. Evaluating these patients will help improve the development of the device and support the future QoL of these patients.

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Statutory Declaration

“I, Charity Nguumbur Inyom, by personally signing this document in lieu of an oath, hereby affirm that I prepared the submitted dissertation on the topic “Understanding the quality of life of patients living with a Left Ventricular Assist Device: A qualitative approach / Die Lebensqualitität von Patienten verstehen, denen ein Herzunterstützungssystem (LVAD) implantiert wurde: Ein qualitativer Ansatz”, independently and without the support of third parties, and that I used no other sources and aids than those stated.

All parts which are based on the publications or presentations of other authors, either in letter or in spirit, are specified as such in accordance with the citing guidelines. The sections on methodology (regarding practical work, laboratory regulations, statistical processing) and results (in particular regarding figures, charts and tables) are exclusively my responsibility.

Furthermore, I declare that I have correctly marked all of the data, the analyses, and the conclusions generated from data obtained in collaboration with other persons, and that I have correctly marked my own contribution and the contributions of other persons (cf. declaration of contribution). I have correctly marked all texts or parts of texts that were generated in collaboration with other persons.

My contributions to any publications to this dissertation correspond to those stated in the below joint declaration made together with the supervisor. All publications created within the scope of the dissertation comply with the guidelines of the ICMJE (International Committee of Medical Journal Editors; http://www.icmje.org) on authorship. In addition, I declare that I shall comply with the regulations of Charité – Universitätsmedizin Berlin on ensuring good scientific practice.

I declare that I have not yet submitted this dissertation in identical or similar form to another Faculty.

The significance of this statutory declaration and the consequences of a false statutory declaration under criminal law (Sections 156, 161 of the German Criminal Code) are known to me.”

Date Signature

Declaration of your own contribution to the publications

Charity Inyom contributed the following to the below listed publications:

Publication 1:

Authors: Charity Inyom, Thomas Haese, Felix Schoenrath, Evgenij Potapov, Jan Knierim.

Journal: Heart & Lung: The Journal of Cardiopulmonary and Acute Care

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Contributions from Charity Inyom included:

1. Designing the study
    a. Conception of study
    b. Obtaining the necessary permission to conduct the study
    c. Choosing the study population
    d. Choosing the sampling method with supervision from Dr. med Jan Knierim
2. Data collection methods and procedures
    a. Interview question (Table 1) formulated by Charity Inyom with supervision from Prof. Ariane Abantal.
    b. Conducting interviews
3. Data Analysis concepts and strategies
    a. Analyzing Data from the translated and transcribed interviews
4. Writing of the submission ready manuscript
5. Ensuring ethical practices were followed correctly

Title: Lived experiences of patients implanted with left ventricular assist devices

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Signature, date and stamp of first supervising university professor / lecturer

_____

Signature of doctoral candidate

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Lived experiences of patients implanted with left ventricular assist devices

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ABSTRACT

Background: Besides survival, improvement in quality of life (QoL) is a major aim of left ventricular assist device (LVAD) implantation. QoL assessment tools in current use are effective in the gathering of standardized metrics but are limited in their ability to elucidate everyday lived patient experiences that also affect overall patient wellbeing.
Objective: To describe and understand the lived experiences of patients undergoing long-term circulatory support with LVAD.
Methods: A phenomenological approach was used. Purposive sampling of consecutive willing inpatients and outpatients living with an LVAD for longer than 6 months was conducted until theme saturation. There were a total of 21 patients interviewed and this was then recorded and transcribed.
Results: A total of eight themes emerged from the data. Overall, the patients' quality of life was affected by: (1) whether they had experienced improvements or setbacks in their recent health condition, (2) experiencing burdens from their device such as weight and handling, (3) limitations in their physical ability such as participating in sports, their inability to work; or reduced sleep, (4) reduced social interactions; (5) reduction in sexual activity and performance; (6) experiencing emotional and psychological problems and experiencing anxiety. Patients highlighted the value of obtaining (7) support from family and friends. The interviews also revealed that some patients experienced the feeling of (8) optimism and obtaining "a second chance" at life.
Conclusions: LVAD patients have unique concerns and lived experiences. Some themes emerging from this interview series such as having to give up work, having reduced social contact, reduced sexual activity and emotional problems, family support structures demand careful attention during the pre-implantation counselling and post implantation ongoing care. These aspects also deserve more attention in quality of life studies among LVAD patients. Patients with recent improvements in health reported a more positive outlook. Overall the majority of patients reported feeling that they obtained a second chance at life.

Introduction

Left ventricular assist devices (LVADs) are a viable therapy option for end-stage heart failure patients not adequately managed on maximal medical therapy.[1] The number of patients undergoing long-term outpatient LVAD therapy either as a bridge to transplantation or as destination therapy continues to increase around the world.[2,3] Studies suggest that the current level of mechanical circulatory support is approximately 50% with LVADs comprising 45% of this.[4] With the increasing number of patients, identifying the long-term challenges and supportive care needs of LVAD patients which affect their quality of life (QoL) has become of increasing and topical priority.

Definitions of QoL vary depending on the indicators, discipline or field and the target groups being considered. This study uses the World Health Organization's simplified definition of QoL, "An individual's perception of their position in life in the context of the culture in which they live and in relation to their goals, expectations, standards and concerns".[5] In relation to heart failure QoL is a multidimensional condition that is shaped by economic and social influences, life satisfaction and the process and severity of the disease.[6] Aspects of QoL that could be affected by LVAD implantation include physical, emotional, cognitive and sexual functioning,[7] as well as complications including infections, neurological difficulties, and device malfunctioning.[8]

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Prior studies[7–10] have shown an improvement in QoL in patients treated with an LVAD. Quantitative instruments, such as the Kansas City Cardiomyopathy Questionnaire (KCCQ), EQ-5D-5L-EQ-5D, Minnesota Living with Heart Failure Questionnaire (MLHFQ) and the new QoL with a Ventricular Assist Device (QOLVAD) Questionnaire are currently the main tools for QoL assessments in the LVAD population. The advantage of questionnaires is their ability to gather a large amount of information within big populations and therefore generate statistical relevance.[11] However, their benefits are limited by potential oversimplification of patients lived experiences. The KCCQ and MLHFQ were established for heart failure patients without LVADs, and thus have limited transferability in reference to the LVAD context.[12–14]

Besides survival, QoL is the aim of every therapeutic intervention. Since patients' everyday lived experiences and concerns, play a central role in their overall wellbeing, a better evaluation of this aspect would offer a more complete QoL assessment as can be achieved from questionnaires alone. The aim of this study was to better describe and understand the lived experiences of patients with an LVAD. By understanding the lifestyle changes, struggles, and altered QoL awaiting them, accommodations could be made to address these challenges.

Table 1
Interview guide.

1. Can you please tell me about your life before the diagnosis was made? How did you know you had a problem? What did you do, how did you feel?
2. How did your life change after the diagnosis? Please can you tell me about your experience since Implantation? What does it mean for you to have this disease.
3. Please can you tell me about your life after the implantation. Have you felt an improvement in your quality of life? Can you give some examples?
4. Do you also have the feeling that something in your life is more difficult now, or is there something that you do not like after implantation? Can you give some examples?
5. Could you please tell me about your daily routine, what does a normal day in your life look like?
6. How did it change before/after the implantation?
7. What about your family and friends, do they notice some improvements? Did they tell you their impressions before and after the implantation?
8. Please describe the relationship you have with the medical staff.
9. Do you get enough support? Do you feel well treated? Did you get answers to your questions?
10. Do you have professional help at home?
11. Based on your experience, is there anything you think can be improved regarding the doctor–patient relationship?
12. Is there anything you would like to do but cannot do because of the implant?
13. Is there anything else you would like to tell me about your before/after implant experience?

Methods

Ethical statement

This prospective study was reviewed and approved by the ethics commission of Charité Medical University Berlin in December 2019 (EA2/144/19). All participants were duly informed of the objectives of the study, and gave explicit informed consent prior to participation.

Design

A phenomenological research approach was chosen as the most appropriate way to capture the patients' lived experience.[11,12] This method offers a structure that enables pattern identification, themes and connections of a person's experience. The qualitative approach to data collection entailed conducting a semi-structured interview that elicited the patients' experience of living with an LVAD. The guide was created by defining and identifying the research question and reviewing other literature regarding lived experience. These questions were shared with a sociologist, who reviewed them carefully. Afterwards, they were tested for effectiveness on two patients outside of the study cohort. An interview guide (Table 1) was used to maintain consistency while allowing opportunities for free responses and theme development.

Participants

A total of thirty participants were identified at the German Heart Center in Berlin, Germany, a non-profit foundation that treats both congenital heart defects and acquired heart diseases of all degrees of severity and for patients of all age groups. It is a high volume cardiothoracic center performing more than 100 LVAD implantations per year. Patients are followed up in an associated outpatient department. Inclusion criteria included living with a continuous flow LVAD for over six months, being over 18 years old and being mentally and physically healthy with willingness to participate. Consecutive patients presenting for outpatient clinic follow-up, that were admitted to the inpatient stations and meeting the inclusion criteria during the study period, were approached for participation. The six month timeframe was chosen so the patients could generate enough life experience with their LVADs. Patients receiving LVAD are initially extremely ill with end stage heart failure and it is expected that the patients typically require several weeks to recover and return to their normal outpatient routines as well as fully adjust to the new life of mechanical circulatory support. Patients who did not visit the clinic during the recruitment period were excluded from selection, however in- and out-patients were included in the sample. Of the 30 selected patients, 21 took part in the interview. The interviews continued until data saturation was reached and no new themes emerged. A total of six patients declined and three died before the interview due to LVAD complications. All participants were duly informed of the objectives of the study, and guaranteed anonymity and confidentiality. All received and signed consent forms.

Data collection

The study was conducted between December 2019 and February 2020. The interviewer was a medical practitioner who underwent training in qualitative research. A sociologist versed in qualitative studies assisted in the selection and confirmation of the topics to be addressed in the interviews. The face to face interviews were conducted in German language at the hospital in a quiet room. Before each interview the patient's sociodemographic information such as age, sex, marital status, job, residence status was collected, with the patient's consent, from the hospital data bank. The sociodemographic status was then confirmed by the patients. A semi-structured interview guide was used to maintain consistency and offer opportunities for detailed responses (**Table 1**). The guide was created by defining and identifying the research question and reviewing other literature regarding lived experiences. These questions were developed by a team of physicians and nurses who were experienced in caring for LVAD patients along with a sociologist with limited LVAD experience. Afterwards, they were tested for validity on two patients outside of the study cohort. The interviewer asked the participants to give a narrative description of their feelings and the meaning of those experiences. The interview lasted between 40 and 60 min and ended when the interviewer believed that all the questions had been answered to the best of the participant's ability. Participants were encouraged to freely express their thoughts and feelings after responding to the questions listed in the interview guide. Follow-up questions were presented to deepen understanding. The interviewer adopted an

empathetic attitude during the interview thereby encouraging the participants to provide open communication. After all the prepared questions had been addressed, each respondent was asked whether they would like to add anything that had not been raised in the interview, to ensure no significant aspect was overlooked.

To ensure understanding and accuracy, all interviews were recorded and field notes were made to capture situational factors and non-verbal communication. The data from the interviews were collected and manually managed in Microsoft Excel.

Data analysis

All the recorded interviews were transcribed verbatim. The Colaizzi phenomenological analysis method was used to reveal emergent themes and their interwoven relationships.[15] This includes a seven-step approach for conducting qualitative research which keeps the researchers close to the data. Using this method, information is gathered from individuals who have experienced or lived in a situation or phenomenon using interviews, journals, and/ or observations. To begin, all patients' descriptions regarding their experiences with an LVAD were read. Comments were marked up to identify themes that stood out. Significant statements were manually extracted coherent to the purpose of our study, based on repetitive patterns in the data. The themes were then organized into categories.

Interpretations based on the common themes that were identified were linked to our patients' lived experiences with the LVAD. These themes were then integrated into an exhaustive description of their lived experience. The final step, using Coliazzi's method, was to return the descriptions to the patients hospitalized after their routine checkup (due to complications of the LVAD) to assess how they compared with their experiences.[15]

The strategies that were used to ensure accurate data collection and analysis included:

(1) Selection of participants who were living with LVAD and willing to participate in the study.
(2) Collective reading of the transcript by members of the team.
(3) Identification and confirmation of themes with the sociologist who separately coded the sample of the transcript as a peer check.

A number of measures were taken to ensure the integrity and accuracy of the findings. It is important to identify personal and team values, assumptions and biases at the outset. The interest in this study comes from the team's medical background and their inquisitive minds. It is acknowledged that certain biases and previous experiences were brought to this investigation, yet these are the same reasons that brought about the investigation of this phenomenon. Preconceived notions which gave rise to the knowledge of not knowing and understanding the patients' lived experience has driven the processes of the study. The goal was to try to consciously suspend any preconceived suppositions regarding the participants lived experiences.

Results

Patient characteristics

The 21 participants were Caucasians (14 males and 7 females) between 37 and 78 years, with a median age of 61 years (IQR: 10). All except one female patient had a partner or were married.

Patients were supported by a Heart Ware HVAD (n = 14) or a Heart Mate 3 device (n = 7). Median time between implantation and interview was 26 months (IQR: 38). All patients were employed before implantation.

Themes

The following themes emerged from the interviews as key aspects characterizing the lived experience of the patients with LVAD devices. These themes appeared in all the interviews, and we indicate where demographic differences in the sample may be relevant. The illustrative quotations from the interviews have been translated from the original German into English.

Perceived overall health status: improvements and setbacks

A total of eleven participants reported that their symptoms had improved after receiving the implant. A 60-year-old male participant said, "I could hardly go up the stairs, these days I can do that, not easily but still better than it was before the implantation". Another 55-year-old female participant said, "When I got sick, I could no longer work in my garden, I was always very weak. I have returned back to my garden since receiving the machine, it has really improved my resilience." Another 57-year-old female participant also said, "My breathing can be better but is still better than before the implantation".

Out of 21 participants, seven reported setbacks. A 61-year-old male participant remarked, "I had problems with breathing and physical strain but since receiving the implant it has become worse, I am very disappointed, and I wish I knew better". Another 58-year-old male participant said, "I don't feel any different with my breathing and my legs are still very much swollen like they were which was the major problem I had. This has not changed."

Limitations of LVAD device

All 21 participants complained of the weight of the device (approx. 5kg). Device weight was reported to impede their free mobility, also causing shoulder, back, and waist pain. A 46-year-old male participant said, "After implantation I really feel the weight of the machine maybe because I lay down most of the time, but since I left the rehabilitation center I feel the weight of carrying the device around." One of the female participants (55 years) made a similar comment, "The weight of this thing (pointing at the machine) is really too much for me, I wish it was a bit lighter, I have so much pain in my back and neck."

A total of fifteen participants complained of limitations imposed by the device battery life. The runtime for the device for ~~our~~ participants was around 10 h (on one charge). A 49-year-old male participant said, "I once forgot the battery while at a social gathering with friends. Soon I noticed the alarm that said I needed to recharge. I was completely distraught and had to end the event abruptly. This made me very frustrated as I felt my life completely depended on my batteries." Another 58-year-old male participant also said, "It is annoying to charge the batteries but luckily we don't have to do that so often, there are worse things than charging a battery."

Furthermore, more than two-thirds of the participants (15 from 21) complained that their cable was too short and were unhappy with how the cables were attached to the outside of their body. "I asked a colleague of yours if the cable can be longer, because I would prefer mine longer," said a 37-year-old female. Another 62-year-old female participant said, "I would like to try a longer cable if this is possible, this one is too short."

For four male participants the cable was not an issue as one of them said, "With my grandchildren playing around when they visit, I think the length is really ok, I still have to take care but I have it under my watch since it's not too long." Nonetheless all participants saw no

alternatives to the current situation and felt they had no option but to adapt to the situation.

Physical problems

Of the 21 study participants, 19 reported a reduction in physical activities such as cycling, swimming, biking, and jogging, with a majority citing a complete cessation of these activities. This change in lifestyle was more of an issue for the male participants than women. One 46-year-old male reported, "Look at my body, you can see I was a body builder, all that is gone now as I can't go to the gym to train anymore." A 37-year-old male said, "I can't jog again, I used jog at least twice in a week, sometimes cycle with my wife on weekends when the weather is good, I can't see myself doing that now, at least not for now". There were two male participants reported never having engaged in such activities prior to LVAD implantation.

Sleep problems were documented among six of our participants (four being female), in particular in regard to difficulty sleeping on the side their LVAD was implanted on. One 54-year-old female participant said, "I can no longer sleep on my left side, before the implantation I loved sleeping on my left side and this has caused me a lot of troubles with sleeping." The remaining participants did not mention difficulties with sleeping as a problem.

Additionally, travel limitation concerned most of the participants. All except two male participants, ages 65 and 70, reported difficulty in traveling and planning for travel. Due to the necessity of packing the batteries and accessories for the implant, travel became more complicated than usual, and the thought of this process discouraged many patients from it. International travel added the risk of the device malfunctioning and the patient being unable to find emergency help. A 61-year-old male participant mentioned, "I used to travel to Thailand or around Asia, now I feel so limited due to this implant that I can not travel for such a long distance." Another 57-year-old male participant raised the problem of checking in at airports. Although some airport personnel were aware of the device, others were not, and sometimes led to him being heavily interrogated. He found this process humiliating and degrading, limiting his travel to within Germany or otherwise short distances.

All participants were employed before implantation, but reported being unable to work afterwards. A former 61-year-old male banker reported, "The worst thing is that I enjoyed my work before the implantation very much, but I was then immediately, I would say, forced to retire. That's a lot of pressure. You can only imagine that if you love your job." These forced circumstances after the implantation of the LVAD were difficult for him to bear. Diagnosis leading to implantation of the device which in turn led to the early retirement of our participants resulted in a loss of income. This applied to both the men and women in our study. A 57-year-old woman said, "I can no longer shop as I usually do because I don't have a job and do not get paid". A 66-year-old male participant said, "Since I only get retirement money, I have to limit how much I spend on everything, the money is very little." All but three participants (two males 78 and 62, Female 70) complained about how little they earned since the implantation. One of the three said, "I had a building firm with a friend, although I have retired now because of my health, I sold off my share of the company for a good price to a friend. I am not a millionaire but I am very satisfied financially."

Social interaction

Of the 21 participants, 17 reported a drastic reduction in social interaction with former colleagues, friends, and family members. This was reported mostly by the men and women within 38–55 years of age. One of the male participants said, "When you do not have money you have fewer friends and cannot go out as often as you did before or hang out with them." Another participant said, "I used to party and hang out with a lot of celebrities when I was healthy, since I got this thing here, my life changed. I don't associate myself with such people or events anymore, I am very sober these days". The women were of the same opinion. One said, "I do not accommodate visitors anymore, only my brother is allowed to come visit me", and another said, "My circle of friends has reduced since I got this device." However, among the older participants this was not reported.

Sexual activity and performance

All but one participant reported that they were sexually active before the implantation, and that the device had reduced or entirely eliminated their sexual activity. The women in our study appeared to be less bothered about this change in life experience than the men. A 55-year-old woman said, "It is no longer the same and it happens less often but I really do not care if it happens or not." Another 54-year-old woman reported, "There is actually no reason to have sex again, since I am scared of something bad happening."

The reasons given among both sexes, predominately men, for the reduced sexual activity were body image issues and reduced sexual function/libido. A total of three male participants said they were ashamed of their bodies and were concerned with how their partners perceived them after receiving the device, and all except one 62-year-old female participant reported a decreased in sexual desire after receiving the implant, in addition to feeling that the complexity of the device hindered sexual activity (i.e., fear that the cable could disconnect during sex caused anxiety). Only one of the female participant's declined to talk about this topic.

Emotional and psychological problems

Participants reported a variety of emotional states during the study. Eight participants (five male, three female) said they were stressed, six (four females, two males) said they were depressed. One 46-year-old man said, "A normal human being should not feel like this, the machine degrades you in comparison to others". This explanation by another patient highlights the multiple changes an LVAD can bring: A 37-year-old woman diagnosed with postpartum cardiomyopathy said, "sometimes I regret having a child, I had a good job and a happy home with my husband, we got pregnant, which was fine, but since I gave birth my whole life changed completely, I can no longer work and due to many problems my husband also left."

A total of 15 out of 21 of our participants reported the feeling of loss. "I enjoyed going shopping with my wife and doing things on my own, but things have changed now as my wife has to do most of the things we used to do together. I feel completely dependent on my wife and other family members", reported one participant. Another 61-year-old male said, "I feel like I have lost everything," and a 54-year-old female said, "I think I have lost my old self completely."

All participants complained of having lost their freedom in different forms, and reported feelings of frustration and low self-esteem. "I feel lesser than other humans" said a 66-year-old male patient. "I am disabled not only physically but also mentally because there are too many things I have to forgo, and my life has been simply reduced to spare parts, without those parts I cannot move or live."

All participants reported device related anxieties that revolved around three major themes: the risk of implant malfunctioning or having complications, social anxieties regarding the perception of the implant by the public or loved ones, and anxieties regarding the future. Patients that expressed worries regarding device malfunction often mentioned the limitations that carrying the device generated. One grandfather complained that this hindered one of his favorite activities, he said, "I love my grandchildren, but I am afraid to play with them because they like jumping around and touching several things at the same time. I am concerned that they might pull off the

cable. So I avoid playing with them." Other participants had worries regarding how others would perceive the device and whether they would become a burden. Seven participants had a particular fear of public transportation: one 60-year-old male participant said, "When I am in the train sometimes people are looking so strangely at me that I feel someone would snatch my bag (holding the device) thinking that I have a lot of money." Another mentioned that he was afraid that the device would cause his wife's caretaking burden to increase to the point that she would consider leaving him. Finally, anxieties regarding the future surfaced as one of the most pressing issues for our participants. Not knowing how long the device would prolong their lives made some very distraught, as they could not make concrete plans concerning the long term future and therefore prevented them from looking forward to things, however this topic was not observed among the older (aged 66+) participants.

Family and friends support

All of the participants reported receiving adequate support from family or friends. More than half of the participants reported that their situation had drawn them closer to friends and family and taught them to value these more. A 64-year-old male participant reported "my wife and my brother have been very supportive." A 70-year-old woman explained, "My daughter moved from Munich to Berlin since the implantation to help me out." Another 61-year-old male participant expressed a mix of feelings about receiving help, "I have so much support from my friends sometimes I feel is a burden but they have been there for me and helping me. He added, "Initially the bureaucratic paperwork (surrounding life changes after receiving the device) was very alarming but I have a friend who is very good at filling out forms, he came over and did all the applications with me." Nevertheless, more than one third of the male participants said they avoided meeting up because they considered themselves a burden to their family and friends.

Optimism

A total of two-thirds of the participants expressed a positive outlook on life as an outcome of having the LVAD. A 37-year-old male participant said, "I am very sure that my health will improve now that I have this device." Another 57-year-old woman said, "Since I got the device I feel a lot better, and am very optimistic about what the future holds, not just as a participant but also that the quality of the device will improve in the years to come."

"I am happy to still be alive", "I am happy this pump has given me a second chance at life", "I have life limitation in return for life prolongation", said a 61, 46 and 78 year old male patient, respectively. A third expressed joy that they could still spend time with their families and use this time to improve themselves, even if they were not as strong as before. Others who had lived unhealthy lifestyles (chain smoking, drug addiction) felt that they were given a wake-up call to live a healthier lifestyle. One 64-year-old male participant reported, "I quit smoking 3 years ago, too late but I did. I am a changed man now."

Discussion

After implantation of an LVAD patients experience a significant improvement in exercise capacity and QoL, according to questionnaires like the EQ-5D-5L and KCCQ.[12,13] However, LVAD patients have unique QoL concerns and neither EQ-5D-5L nor KCCQ are designed to assess lived experiences and challenges LVAD patients face after the implantation. Furthermore, individual perception, coping and response to these everyday experiences remains largely unexplored.

Our current study identified certain themes the patients considered to be important for their QoL. We found that concerns regarding QoL were equally divided between the sexes for six out of the nine categories in our study. Only for the categories physical and sexual problems, social interaction, and fear did the male participants express more concerns than the female participants, with the exception of sleep issues, where our female patients recounted more burdens. Older patients generally had fewer to no concerns regarding fears and social interactions.

Patients provided details of limitations inherent in the LVAD device itself, including the battery size, driveline length, and the size of the device. Some patients expressed anxieties regarding their inability to control the device and how sensitive it was. A study by Adams and Wrightson[10] also discovered similar psychological burdens for LVAD patients such as fear of complications and dependency on the device. LVADs have markedly decreased in size in the past several years,[16,17] but further research to develop less cumbersome devices will be of great benefit to patients. Furthermore simple changes such as adjusting the length of the cable might cause significant relief.

Although it is known that LVAD implantation can lead to early retirement[18] this item is not included in the usual questionnaires given to patients, therefore participants are usually limited in their answers to their experiences in this area. Our study revealed early retirement and the inability to work to be a major issue for patients post-implantation. All of our study participants mentioned that this resulted in many psychological, social and financial problems. These concerns should be alleviated by providing new possibilities to return to work or a modified job placement, accelerating their return to normality.

All participants in our study remarked that they had a closer relationship with their partners and valued their partners more after the implantation. This finding is in line with other studies that found that patients experienced more closeness, intimacy and bonding with their partners as a result of increased dependency of the patient after implantation.[19]

The lived experience of patients with their sexual functioning is not directly addressed in existing questionnaires, thereby limiting the expression of patients in this area of life. All the participants in our study were sexually active before receiving the implant and became inactive afterwards as a result of body image concerns or concerns with the device malfunctioning during sexual activity. Although it is known that patients are able to find ways of expressing their intimacy without sexual intercourse, sexuality remains important for QoL.[19] This obstacle could be improved through psychotherapy and partner therapy.

Post implantation outcomes such as bleeding, infection, pump thrombosis, right heart failure, device malfunction and stroke contributed to reduced QoL for patients.[20] Although patients are clearly informed regarding possible complications and outcomes of implantation, our study also confirmed that the patients often had high expectations for how the implant would benefit them.[21,22] Medical personnel have the responsibility to help patients manage these expectations by clearly providing realistic information and estimates regarding recovery and possible complications. Families should be thoroughly prepared to cope both physically and psychologically with these changes.

Other studies have discussed depression and anxiety in patients.[23–25] These factors are associated with a worse prognosis for heart failure.[23] They can lead to medical incompliance which is further associated with an increased risk of hospital readmission.[25] The participants in our study similarly showed increased anxiety and depression. Nevertheless, they were still optimistic that their conditions would improve and grateful for receiving the device, as well as happy to be alive because of it. Psychological support could

lower the burden of the disease and positively improve the outcome of patients.

Social interaction decreased among patients in the study as a result of early retirement, financial loss, fear and body image problems. This has not been clearly reported in the existing literature. Support groups and other support strategies should be further expanded. Social media[26] have been shown to be useful as a virtual community for LVAD patients (e.g., MyLVAD), providing advantages such as patient education, shared decision making, and psychosocial support. Access to social media should be strongly encouraged for those living with an LVAD.

Limitation and bias

The study was conducted at a single center. The findings in a qualitative research study cannot be tested for statistical significance and the data obtained cannot be extrapolated to the general population. To validate these findings, multiple studies should be conducted at different centers with a wider population. This study was conducted only in a single high volume center in a highly developed European country. There may be cultural differences with other countries. Germany has a well-developed, universal healthcare system, and this may have influenced the experiences of the participants regarding QoL. Participants in our study had their LVADs implanted for at least six months. This may have caused some selection bias, in that sicker and more unstable patients that did not survive the initial six month period were excluded from sampling. That said, given the fact that the majority of LVADs are implanted in wealthy countries and in most cases in relatively large well organized hospital settings, we believe the findings will be of value to the majority of clinicians taking care of LVAD patients. The socio-economic status was not considered in our study as a variable and future studies would benefit from this.

Conclusion

The findings in this study provide an enhanced understanding of the experiences of LVAD recipients and underscore the importance of truly listening and responding to their concerns. It also highlighted the significant emotional impact the implant had on the patients and the need to develop peer support networks and programs. The LVAD has saved the lives of many patients suffering from end stage heart failure. Each patient interviewed adapted to the device in their own way. Although studies show that patient QoL improved in most cases, our study provides evidence that LVAD-implantation has a tremendous impact on the lived experience of these patients, revealing many areas for improvement. The study may help healthcare workers and device manufacturers to renew their focus on improving the lives of LVAD patients, particularly in patient follow-up care and the mechanics of the device.

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Declaration of Competing Interest

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Curriculum Vitae

Mein Lebenslauf wird aus datenschutzrechtlichen Gründen in der elektronischen Version meiner Arbeit nicht veröffentlicht.

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