Balancing normalcy and safety: health-related needs in patients with a ventricular assist device within their home environment

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Aims
Ventricular assist device (VAD) implantation has become a well-established treatment strategy for patients suffering from advanced heart failure. Ventricular assist device treatment attempts to ameliorate the symptom burden but may create new challenges in patients’ lives. Lacking are insights into perceived challenges and health-related needs of patients with VAD within their home environment. Our study aimed to explore the perceived health-related needs of patients living with a VAD in their home environment.

Methods and results
We used a qualitative approach based on a hermeneutic, directed content analysis design. Telephone-based interviews were conducted with 10 patients with VAD from a single cardiology centre in Germany. Data collection and analyses were carried out using content-structuring content analyses. Normalcy and safety were identified as overarching themes: participants expressed a need to balance daily activities between striving for normalcy and maintaining safety. Underlying necessities reflecting this balance were categorized as functional, social, and mental health-related needs. Learning by doing, social, and peer support were described as relevant requisites. Fulfilling these health-related needs could aid patients living with VAD in achieving the sense of normalcy and safety they seek.

Conclusion
Balancing health-related needs with striving for normalcy and safety, emerged as a new core concept for patients with VAD. Thus, being cognizant of this balance when caring for these patients, could facilitate coping after VAD implantation through increasing acceptance of limitations to daily functions by enhancing individual safety. A supportive social environment, including peer support, becomes vital in self-management programs preparing patients with VAD for their home environment.

Keywords
Ventricular assist devices • Health-related needs • Outpatients • Coping • Qualitative Research

Implications for practice
• Needs should be addressed by patient-specific self-management interventions.
• Education should address the desire for normalcy and safety.
• Social and peer support may facilitate reintegration.
• Detailed analyses for subgroups are necessary.
• Emotional needs should be examined.

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Introduction

Prevalence rates of patients with chronic heart failure have grown exponentially over the last two decades. Due to demographic changes in the western world, a further increase can be expected in the coming years. In patients, where optimal medical treatment options are exhausted, ventricular assist device (VAD) implantation has become an established treatment strategy. Ventricular assist device treatment attempts to ameliorate the symptom burden in chronic heart failure patients, e.g. dyspnoea and fatigue. Patients may live with VAD for years within their home environment due to technical advancements and donor organ shortages. Combined with a growing number of non-transplantable patients, VAD implantation, as a destination therapy, has increased with nearly 50% of patients living with a VAD until the end of their life.

Dependency on an external device exposes patients to new challenges and diverse needs in self-management. Relevant examples include wound care, technical device handling, infection prevention, monitoring of vital signs, anticoagulation, and medication regimes. Furthermore, VAD therapy leads to challenges and constraints in daily life and lifestyle, for example dietary restrictions, cessation of tobacco use and alcohol consumption, as well as physical impairments and disturbances in sleep and sexual activity.

Descriptions of patients' experiences and adaptation to these challenges upon returning home following VAD implantation, were obtained from a qualitative meta-synthesis using the coping model by Lazarus and Folkman as a reference. In support of this model, Abshire et al. described the coping process as the transition from early to late home stage, occurring approximately between three to 6 months on VAD therapy.

The early home stage, the period directly after VAD implantation, is characterized by challenging adjustment processes: the home environment needs to be adapted to the VAD, and the VAD may dictate and restrict several aspects of daily life. Most patients describe feelings of dependence from the VAD itself, as well as from relatives and caregivers. The dependency of one's own life on a technical device can heighten feelings of strain, which may manifest in overreachings, and may lead to sleep disturbances and overcautiousness. These restrictions may lead to changes in social behaviour, when patients cannot participate in social events or maintain former roles in the family and/or workplace. When those reach the late home stage (VAD use for about more than 6 months), most patients describe a successful coping process: they experience increased physical functioning and a better quality of life.

Adjusting to new routines enhances safety and living with a VAD can be accepted as the new normalcy.

Language available to date, lacks information with respect to the subjective health-related needs from the perspective of the individuals during this coping process (specifically within the early and late home stages). Thus, the aim of this study was to explore the health-related needs of patients with VAD in the early and late home stages.

Health-related needs were distinguished from generic human needs using the World Health Organization’s (WHO) definition: ‘need for health services as experienced by the individual and which he/she is prepared to acknowledge’. Thus, the following question was asked: ‘What health-related needs do patients with VAD perceive in order to cope with the challenges within their home environment?’ This study was part of a larger project.

Methods

Study design

Our research question comprised both explorative and directive elements. Therefore, a qualitative approach was chosen. The methodology was based on the epistemological hermeneutical spiral found in the works of Dilthey and Heidegger, as described by Lamnek and Krell. Their philosophical work assumes that hermeneutic understanding occurs through the interpretation of expressions of being, in the greater context of history and lived experiences. The design of this study followed the description of the directed content analysis by Hsieh and Shannon.

Consequently, the pre-understanding of the topic in terms of challenges and constraints after VAD implantation, could be integrated and expanded through the participants’ individual perceptions of health-related needs. Interviews with patients with VAD during the early and late home stages were conducted based on a semi-structured interview guide. Use of a content-analytic framework allowed a deductive-inductive process by creating a priori categories and exploring new emerging topics in the analytic process.

Ethical approval was obtained from the Institutions’ Institutional Review Board (IRB) (303/19). This study adhered to the principles of the Declaration of Helsinki. For the description of methods and presentation of results, the standards for reporting qualitative research were used.

Sampling

Participants were recruited from one VAD outpatient clinic in Germany. Purposeful sampling was performed using criteria with potential impact on illness-experience and coping, to generate a heterogeneous sample with different perspectives and insights.

Inclusion criteria defined participants as patients on device therapy from 3 months to 3 years, thus implying a stable health condition in the early and late home stages. Participants were required to have lived at home a minimum of 2 weeks following discharge from rehabilitation.

As development tasks vary over a lifespan, different perspectives on coping and illness after VAD implantation may reflect an age-related effect. Therefore, we aimed to include patients of different age groups, to address this possibility. Furthermore, the female perspective, typically underrepresented due to fewer women with VAD, was intended to be included to consider gender-differences over the course of illness in the patients recruited for this study.

Further inclusion criteria included a minimum age of 18 years, ability to provide informed consent, German speaking, and physical and psychological stability. Exclusion criteria were patients in a palliative situation, defined by the dying process, or when discontinuing VAD was under discussion. Attending physicians of the VAD outpatient clinic performed patient recruitment and subsequent sampling.

Ethical considerations

Participation was voluntary and supported by written informed consent. Data protection and pseudonymization adhered to the German data protection law. Before interviews commenced, participants were asked about their current subjective well-being and provided once again their oral informed consent. Furthermore, participants were asked to select a convenient place for the interview and to ensure that a relative or caregiver be present, if needed. As a prerequisite, psychological and medical
support from the VAD outpatient clinic was available during and after the interviews for each participant.

Data collection and analysis

Data collection and analyses were performed simultaneously. The first author conducted the telephone-based interviews, and audio-records were transcribed immediately after the interview. The semi-structured interview guide began with a narrative entry for the participants to reflect on their initial time after and memories of the VAD implantation. This section was followed by a thematic synopsis of challenges and constraints outlined from the abovementioned literature (Table 1). This part was used by the interviewer to inquire how participants met these challenges with respect to coping strategies, resources available and needs to improve. New emerging issues were noted and incorporated into subsequent interviews.20

The first author transcribed and qualitatively analysed the data from each interview using the software MAXQDA (VERBI 2020). Transcription followed simple rules, as only relevant passages were transcribed verbatim, approximating the written language.24

The transcripts were analysed following content analysis as described by Kuckartz.24 This content-structuring content analysis refers to the hermeneutic spiral through an iterative approach whereby interpretations from the material can be compared with pre-existing findings. For initializing text work, transcripts were read intensely, and important passages were identified. In the first coding process, the material was coded according to an a priori categorical system, constructed using the topics from Table 1. Other relevant statements were coded thematically.24 The next step, the development of main categories, was done by transforming coded limitations and challenges into health-related needs, as exemplified in Table 2.

This approach enabled the researchers to create categories reflecting health-related needs as perceived by the individual participants. Further analyses involved coding the material with respect to the main categories, searching for overarching themes and subcategories, and concluding with a differentiated categorical system.24

To enhance trustworthiness, emerging topics from the interviews and interpretations during the coding process were repeatedly discussed with peers within the research group.25 The two-step coding process allowed the researchers to compare interpretations and categories with the original data. Purposeful sampling enhanced the transferability of the results to the population of interest.24 Other strategies included memo-writing throughout the process and disclosing former strategies of the researchers about the research topic through the deductive-inductive way of perception that structured the interview guide.24

Table 1 Thematic section interview guide

- Structure of daily life
- Constraints by VAD
- VAD management
- Safety/alertness
- Social (role-) changes
- Social support
- Learning and excessive demands
- Intimacy
- Emotional aspects

Findings

Ten patients on VAD support were interviewed between October 2019 and January 2020. Interviews lasted from 18 to 46 min with an average mean of 32 min. There was one female and nine male participants between the ages of 30 and 75 years. Four participants had VAD implanted over the past year, another four patients between 1 and 2 years, and two participants for 2–3 years.

The findings from the interviews indicate that despite comprehensive follow-up care after hospital discharge, patients with VAD may still have subjective health-related needs. Two health-related needs were identified as an overarching theme: participants expressed a need to balance daily activities between striving for (i) normalcy and (ii) safety (Figure 1).

This overarching theme can be described as a delicate balance for perceived health-related needs. These underlying fundamentals were subsumed as functional, social, and mental health-related needs. Learning by doing, social support, and peer support appear to be interrelated necessities to support achieving and maintaining the balance of daily living with normalcy and safety while living with VAD.

Normalcy and safety

Participants’ statements revealed a strong desire for obtaining normalcy, as pivotal motivation in the handling of VAD-related challenges:

To preserve or regain as much as possible from what you had before. (ZM, line 4)

However, this desire for normalcy was limited by a need for safety through dependable VAD function:

On the street, little children can see my back. I thought if one [of them] sees the cable and pulls it, I would be in trouble. This is probably true with sports [...] It doesn’t work. (MT; line 25)

This participant (MT) described how the need for safety limited the perceived opportunities to carry on with daily activities. On the other hand, the importance of recent activities for the participants influenced their efforts to find appropriate alternatives. Surrounding infrastructure was important to enhance perceived safety, whereas perturbations could enhance anxiety and distress:

It is plausible for a tree to fall in the woods, which could, in turn, lead to a power outage. It repeatedly happened that the VAD alarm was triggered due to no electricity. However, when electricity fails in the night, comes back and fails again, I can’t sleep. (VL; line 33)

A secure power supply, as well as assured specialized medical care, enhanced the possibilities for travelling and visiting friends or family. Therefore, as safety perceived by the participants increased, the easier it was to experience a sense of normalcy. Furthermore, integrating VAD-related tasks into daily life increased familiarity and thus, were more easily included into the new normal.
Alternatively, perceived risks of complications led to the delegation of VAD-related tasks, for example driveline care, to professional nursing services.

**Balancing health-related needs with normalcy and safety**

The strive towards normalcy and safety was again apparent when the health-related needs of patients were examined. This concept was manifested through patients’ expression for improved functional, social, and mental capacities.

**Functional needs**

Participants described feelings of self-consciousness when in public, primarily due to VAD visibility. Concealing the visible device parts helped patients to feel more normal, while maintaining VAD safety in public areas.

Burdensome battery and controller weight led to the issues of wearing comfort, mobility, and adapting the environment:

> The belts you get are useless. They are so heavy [...] because the bags containing the batteries are so bulky. (KN; line 4)

To facilitate activities of daily living, participants used backpacks, waistcoats, and belt bags to store external VAD device parts. Moreover, they adapted their environment to include additional installations, to secure device parts while performing daily tasks, for example showering. Complementary, participants sought to achieve a fitness level that allowed them to perform normal activities:

> I don’t want to run a marathon. I just want to be able to go outside and exercise, something not possible before. (KN; line 16)

**Social needs**

Maintaining social contacts was important for participants. Limitations arose regarding battery-life longevity and means to recharge when necessary:

> When going out at night [...], either you changed the batteries before leaving home when expecting it might take longer, or alternatively you had to leave and go home early. (PT; line 51)

Prejudices arouse in the social environment of the participants as a result of a limited understanding of VAD function and utility, thus leading to the need for comprehension. This was specifically true when the possibilities of living with a VAD were under- or overestimated by family members and friends.

Being productive was a social need that fluctuated between striving for normalcy and safety, including financial consequences:

> And then I said to myself, ‘Why should I expose myself to all the stress at work? Maybe something (complication) is more likely to happen’. (KN; line 16)

**Mental needs**

Developing routines and implementing task-related reminders, as well as memory support by others, were health-related needs expressed by study participants, in order to provide stress relief from daily VAD-related responsibilities. This includes VAD technical handling and medication intake:

> In the evening, once batteries are put back in place, I know, there are pills again, so I cannot possibly forget them. (EM; line 29)

Following VAD implantation, acceptance and feeling hopeful were difficult to achieve. Acceptance was supported by feelings of gratitude and the realization that no alternative treatment options exist:

> You just come to terms with it. You tell yourself you cannot survive without the device. [...] I am so grateful, that this system even exists. (ZM; line 14)

Despite an increasing device acceptance over time, participants also relied on hope for technical advancements and the possibility of heart transplantation.

**Learning by doing, social-, and peer support**

VAD-related challenges were also influenced by the health-related needs for learning by doing, social-, and peer support. Learning by doing was expressed as a need for one’s own experiences in the handling of specific situations with a VAD:

> So much stuff you need to carry around as soon as you are back home. You are advised as to how to handle everything, but you have to practice [...]. There is no right way, you have to learn it by experience. (PT; line 93)
Social support was a strong health-related need for participants, specifically for those in the early home stage, because daily life routines, in combination with VAD specific tasks could not be completed alone. Family members helped with housekeeping, medication management, and performing dressing changes.

Study participants appreciated the advice of other VAD recipients. Peer support occurred during the hospital stay or rehabilitation, in the outpatient clinic, or via social media:

Sharing experiences should be done more often. A group where you get to know each other, and meets sometimes. That would be interesting. (ND; line 47)

**Discussion**

Findings from this study present important insights into perceived, subjective health-related needs of patients in the early and late home stages following VAD implantation. We found that the interrelated, health-related needs for normalcy and safety created a delicate balance in patients’ daily life with ongoing VAD support. Health-related needs could be divided into those with a functional, social, and mental nature. The strive for normalcy and safety, rooted in VAD-related challenges, was influenced by learning by doing, peer- and social support.

The concept of normalcy refers to patient expectations when living and coping with chronic conditions. Achieving perceived normalcy occurs through regaining control over and integrating health-related tasks and constraints into daily life. Similar to chronically ill patients, patients with VAD cannot achieve their former normalcy. In our study, the desire for normalcy was interrelated with the need for maintaining safety. Whereas Abshire et al. point out overcautiousness and permanent alertness in patients with VAD in the early home stage, our findings reveal a more intentional balancing act between an attempt to regain normalcy and perceived risks for complications while performing daily activities. Appreciating the drive towards achieving normalcy while fostering the awareness of safety issues, may help patients with VAD to accept some limitations, ultimately leading to improved coping mechanisms in the late home stage.
Previous studies outlined functional handicaps in patients’ immediate environment due to the VAD weight and uncomfortable wearing apparatuses, as well as difficulties in the selection of clothes. Our participants described creative solutions to enhance mobility and wearing comfort using individual wearing systems to perform daily activities, while balancing both perceived normalcy and safety concerns. These adaptations combined with mastering VAD-related tasks explain the high learning pressure in the early home stage. Our findings suggest that routine development and memory support are pivotal health-related needs that should be considered as educational interventions to decrease distress during the acclimation and adaptation processes.

Learning by doing was described elsewhere as exhausting the limits of the VAD, by trial and error, on behalf of striving for normalcy. Peer support can facilitate learning by doing through shared experiences. Moreover, networking with other VAD recipients may consolidate patients’ identity and support their perception of normalcy.

Another study illustrates the lack in our understanding regarding the functionality and life with a VAD, leading to anxieties and prejudices within the social environment of patients with VAD. As a result, family and friends may become overcautious or ultimately withdraw socially from the patient with VAD.

Nevertheless, congruent with other studies, our findings reveal a high health-related need for social and caregiver support in the early home stage. A high degree of social support may have a positive impact on perceived stress levels, anxiety, and depressive symptoms for patients with VAD, emphasizing the relevance of patients’ social environment. Adjusting experiences reported by other patients with VAD with subsequent integration within the social environment, as well as the ‘know-how’ of surrounding health care providers, may enhance less experienced patients with VAD’s social re-integration, further balancing perceived normalcy with safety measures.

The need to be productive, described as having a meaningful occupation rather than merely employment, is supported by previous findings. Decisions regarding the return to work or contemplating retirement, seems to be a common issue for patients with VAD when striving for normalcy and abiding by safety precautions.

The health-related mental needs revealed in this study appear to be more generic: acceptance, hope, and stress relief; all of which are important concepts in the coping process of chronically ill patients. Feelings of gratitude may function as a specific resource and mediator for patients with VAD to support a favourable coping process.

Limitations
Our study has several limitations. First, the participants of this study were recruited from a single cardiology centre in Germany. Therefore, the transferability across hospitals within Germany, as well as in other countries, may be limited. Second, despite attempts made towards a purposeful sampling, our sample cannot be considered representative. We were not able to recruit more than one female participant to establish a better gender balance and/or merely consider the female perspective. Due to the inclusion criteria, our participants were in a stable physical and mental condition, which may have led to an underrepresentation of patients with unsuccessful coping strategies. Younger age groups were underrepresented and most of the participants were already in retirement; however, suggestions regarding changing needs over the lifespan remain relevant.

Altered memory recall of participants over time may be another limitation.

Furthermore, the use of telephone-based interviews could have missed pertinent nonverbal communication while fostering a limited (less close) relationship to the interviewees. On the other hand, more anonymity may have enabled the participants to speak more frankly about intimate topics.

Lastly, the interviewer had no psychological qualification and may not have been able to sufficiently put patients’ emotional needs into context.

Conclusion
The findings of this study are consistent with other related studies regarding adaptation, coping and experiences of patients after VAD-implantation. They further enable the formulation of relevant health-related needs of patients with VAD under outpatient care. Our model points to functional, social, and mental health-related needs, as a means to maintain a balance between normalcy and safety. Learning by doing, social-, and peer support were relevant mediators of other health-related needs. The consideration of our model may help to improve the care given to these patients through an individualized self-management education. Further research should focus on emotional needs. More detailed analyses of the development of health-related needs over the illness course would be useful, as well as information related to different subgroups that could not be analysed in our research. Future research should establish interventions to better respond to the health-related needs of patients with VAD, including technical advancements that address the interpersonal relationship between leading a normal life while taking safety into consideration.

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Data availability
Original data cannot be provided for ethical and data protection reasons.

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