A Qualitative Study of the Psychological Experience of Patients During and After Mechanical Cardiac Support

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Objectives: Treatments for end-stage heart failure include medical therapy, heart transplantation, and, more recently, implantation of a ventricular support assist device (VAD). Little is known about the psychological adjustment and quality of life of these patients and how patients with a VAD in situ compare with those who underwent transplantation or had the device explanted. Design and Methods: A cross-sectional study using grounded theory methodology was carried out. Patients with heart failure living with a VAD and those who underwent transplantation or explantation were interviewed to elicit perceptions of their adjustment and quality of life. Results: All patients identified perceived control as their core category, with 3 related conceptual categories: normality, uncertainty, and emotional state. Identity of illness/VAD and the impact of the device were specifically identified by VAD patients, and independence was identified by transplant patients. Conclusion: This study has identified previously unrecognized concepts in the adjustment of patients with either a VAD in situ or who have had the device explanted or have undergone transplantation. It provides a basis for the development of specific nursing and psychological care designed to support this developing surgical practice. KEY WORDS: heart failure, perceived control, VAD

As increasing numbers of patients with heart failure are diagnosed in the United Kingdom each year, the challenge to treat those with end-stage heart failure becomes ever greater. Transplantation has been the treatment of choice for such patients, with a 1-year survival rate of more than 85% in the current era and 10-year survival rate of 50%.1 Although a small proportion of patients find it difficult to adapt functionally after transplant, it is clear that the majority experience increased vitality and energy, a greater range of physical activities, social functioning, less sleep disturbances, and a reduction in health-related anxiety.2–5 However, because of the scarcity of donor hearts, there has been an increase in the waiting time for a suitable organ, which has had a significant impact on long-term survival. The introduction of ventricular assist devices (VADs) into clinical practice within tertiary cardiothoracic hospitals in the United Kingdom has allowed patients with end-stage heart failure to receive a VAD as a bridge to transplant or myocardial recovery.6 Initial results indicate that VADs are providing significant benefits to mortality compared with medical therapy treatments.7 Studies addressing psychological adjustment have found that the quality of life (QoL) of VAD patients most closely resembles that of transplant recipients,8 but in one of the few studies to compare patients with a VAD in situ with those who had had the device explanted or who had subsequently undergone transplantation (hereinafter referred to as explant and transplant patients, respectively), QoL and psychological adjustment were worse in those with the device in situ.9 However, data remain sparse, and it is unclear how the specific idiosyncrasies of these devices, such as the intrusion into daily life and the need for invasive monitoring, affect the patients’ psychological adjustment and well-being. Furthermore, although research has begun to identify areas of psychological well-being that are affected by living with a VAD, there has been little investigation to illuminate whether there are differences in psychological processes.
relative to the adjustment of both transplant and explant patients.

The purpose of this study was to identify the psychological processes that patients use to construct and make sense of their adjustment to a VAD and to determine whether the conceptual construction of adjustment and well-being in heart failure patients is consistent for patients with different surgical outcomes.

**Method**

**Participants**

Study participants were recruited from the VAD program at our institution. All patients on this program (N = 24) were invited to participate in this study. A total of 11 participants (8 men and 3 women) gave written consent to be interviewed, and from this group, a purposive sample was used for each round of interviews. Four patients were interviewed while living with a VAD in situ, 4 patients were interviewed while being maintained on anti-heart failure medication after the explant of a VAD, and 3 patients were interviewed after receiving a cardiac transplant after a period of time being supported by a VAD. The age of the participants ranged from 18 to 60 years (mean [SD], 42.9 [13.5] years), all had received a secondary school education, and 63% were married or cohabiting. Six patients had been diagnosed with dilated cardiomyopathy and 5 had been diagnosed with ischemic cardiomyopathy, with a mean (SD) time since diagnosis of 3.4 (3.9) years. All participants were clinically stable at the time of the study. Of those with a VAD in situ, 3 participants had a HeartMate 1 and 1 participant had a Thoratec device. For the VAD group, mean time since implantation was 11 months, and in the transplant and explant groups, mean time since device removal was 20 and 9 months, respectively. All participants were medically retired at the time of the study. This population, although small, was representative of the entire VAD program at this time. The patients who participated did not differ in current status (VAD in situ, explant, transplant), diagnosis, sex distribution, age, educational level, or marital status from the nonparticipants.

**Procedure**

Ethical approval for the study was obtained.

Participants were recruited either when they were an inpatient or when they came to their routine outpatient clinic. Each participant was given written information about the study and given 24 hours to consider whether they wished to participate in an interview. An interview was arranged at a convenient time for the patient, and all interviews took place within the hospital setting. Informed consent was obtained to audiotape the 1- to 2-hour interview to facilitate accurate data analyses through transcriptions. The interview guide was organized around topics identified in chronic illness literature as generally relevant to psychological adjustment and well-being. Topics covered included health history, attributions of heart failure, the illness/surgery experience (VAD/transplantation/medication), adjustment, and QoL.

Patients were invited to communicate their stories as they wished and to end the interview if they chose.

**Interview and Analysis Framework**

Data collection and analysis were based on the grounded theory approach. The process began with open coding, a process of “fracturing” the data into concepts that can be labeled and sorted while the analyst remains “open” or unrestricted by predetermined theory. Discrete concepts including events, feelings, or actions were grouped under category labels. Each category of concepts was considered in terms of its characteristics, and each instance was compared with other instances in the process of constant comparative analysis, a hallmark of grounded theory. Explanations for differences were sought, the categories were related to other categories, and a theoretical interaction began to emerge for further exploration. After coding the first set of 7 transcripts, we divided our collection of important concepts into a code list of 7 conceptual categories. Two of those emergent categories (control and normality) seemed to be more prevalent than the other 5 conceptual categories, and a close link was found between them in most transcripts. The 7 transcripts were examined again, extracting text excerpts under each category in growing representations of the range of variation within each category.

A second round of a further 7 interviews were subsequently conducted to explore differences related to need for control and normality in the process of adjustment. The theory was expanded to new contexts by deliberately varying the sampling criteria and focusing questions to the additional participants on the relationships between these 2 interrelated concepts.

Records of data collection and analysis were kept in the form of memos, graphs, and informal notes on the conceptualizations that emerged from each coding session and served as the foundations of the theoretical statements. In addition, to assess the stability of the data analysis and interrater reliability, 2 independent raters analyzed the interview data concuring on the conceptual categories. In this way, the findings of the study were developed from the beginning of the analysis process, and the data selection, coding, analysis, and redirection of data selection...
proceeded in a cyclical fashion until no new concepts that related to the central concept of adjustment were discovered and data saturation had been reached. This occurred by the end of the second round of interviews, analyzing the last set of interviews. The process was found to be stable throughout the 14 interviews, and therefore, theoretical statements, except where indicated otherwise, apply to the entire sample.

Results

The analyses indicated that there was one core category related to psychological adjustment, with 6 conceptual categories associated with the core category.

Control

All patients identified perceived control as the core category of their cognitive construction of QoL. For all patients, 3 conceptual categories were identified as being directly related to control; these were patients’ construction of their normality, their emotional state, and thoughts and feelings regarding uncertainty about the future. Two other conceptual categories were identified specifically for patients currently with a VAD in situ; these were the impact of the VAD and the illness/VAD identity. One other conceptual category identified the need for independence, particularly for explant and transplant patients (see Figure 1).

Perceived control was identified as a dynamic cognition that fluctuated in response to many health-related events. Patients constantly attempted to retain or gain control. Changes in environmental circumstances, such as being hospitalized for extended periods of time and then being discharged home, impinged directly on their ability to remain in control of their daily lives.

The process of gaining control was facilitated by rationalizing, or making sense of a new phase in their treatment or illness prognosis or by gaining awareness of environmental challenges.

I think as you reach what might be a plateau in the treatment, your level of control changes, the control of what you can do physically, the control over your spatial parameters...but at the moment, I'm imprisoned within the ward, or within my own house, so I've lost control over movement. (VAD patient).

Control was important for patients to make sense of their prognosis, mental well-being, and social

![Figure 1](image-url)
world over which they subjectively perceived they had minimal control. Patients identified the need to be in control of even a small part of their lives, and this need came from their current dependency on medical staff, family (carers), and medical treatment. Behaviors that were familiar to patients provided a sense of control:

Being in control means doing the same sort of things I used to do before I had the heart problem. (Explant patient)

Maintaining control was an important experience for all patients owing to the loss of control that they had all experienced at some phase during their illness. Loss of control was invariably retrospectively experienced by patients when they were able to recall events leading to a serious or sudden deterioration in their health that needed urgent treatment. Patients subsequently acknowledged the need to feel in control of their lives and be actively engaged in various activities that helped them to regain control:

I find myself more determined to do gym work and things like that. I'm starting to enjoy it more and I force myself to go for walks which also helps me feel good and in control. (Explant patient)

Normalization

The conceptual category identified as normality was an important process of rationalization for all patients and was one of the most referenced concepts associated with perceived control. Patients talked of normality as “feeling normal,” “doing normal things,” and “not feeling different to other people.” It was clear that “being normal” referred to feelings and emotions, personal behaviors, and roles within society. Similarly to control, it was apparent that patients proactively attempted to normalize their experiences and were engaging in a dynamic cognitive process. All patients highlighted the importance of feeling normal to gain control over living with heart failure and their particular treatment.

It is the lack of control that makes you feel different; it is normality that is affected by control. (VAD patient)

Subcategories of normality were important for defining its parameters. Cognitive and behavioral markers of normality were identified by routine, others’ perceptions of them, social and personal comparison, and the impact of the heart failure and the VAD on their family.

All patients focused on the importance of building a new routine or a collection of routines owing to the disruption caused by the illness and the treatment. This was a very practical evaluation of whether their capacity was normal. In addition, vocational and social lives had to be restructured because of physical limitations and a rigid medical regimen incorporating regular visits to the hospital. It was also important for all patients to create a routine that could allow them to feel normal but that would fit with their physical capabilities and rehabilitation. Patients actively engaged in problem-focused coping by finding activities that would create a routine that was as normal as possible.

In addition, VAD patients were concerned about their physical appearance with the device. Appearance/body image was also a relevant category for explant patients if left with a hernia once the VAD was explanted.

I know it [VAD] is there to keep me alive but I also feel different from anyone else, as I’ve got the VAD on the outside and you can’t just put a coat over the box [portable battery trolley]…you feel embarrassed with it, because I don’t want to be different to anyone else. (VAD patient)

To normalize their experience, patients compared themselves with others or with their own pre-illness health status. It seemed that this strategy provided patients with information that enabled them to validate and normalize their treatment and illness experiences. Social and personal comparisons seemed to reassure patients that they were managing well and that the treatment was efficient. While in hospital, patients were able to see other patients with a VAD or with more complicated medical problems than themselves. In such circumstances, social comparison generated understanding among patients that their stressful situations and reactions were not caused by some personal unique problem.

I was relieved when I was told I had heart failure, because the only other option there could have been was actually a bit more serious…. You always think of a range of things and then you’re glad that this is not that serious. (Explant patient)

Many patients believed that their situations were less stressful than others’ and that they were managing in comparison with others. At times, personal comparison was negative as patients remained focused on the unrealistic expectation of returning to their pre-illness normality. Patients who used acceptance and learned to live with a new normality regained control faster than did those who had unrealistic expectations.

I had a very successful business, I was doing very well and had planned my future with it, and suddenly…it's cut away! It does affect you a little bit, and then you move on. Exactly the same thing with daily activities you want to do. I know what I can’t do and I go on with the things I can do, and that’s the way I cope with things. (Transplant patient)

The impact on patients’ families was also a significant factor for patients’ ability to rate their concept of normality. Families needed to cope with
demanding medication regimens, repeated hospitalizations that disrupted the family routine, and changes to the family caregiving and vocational roles. Often, parents or partners became carers, meaning that they changed their main role and may have had to give it up. In some cases, family members spent more time together than ever before, and this was generally perceived as a positive outcome of the illness as it allowed the patient to develop a closer relationship with others that previously did not exist. Once patients left the hospital, some experienced conflict when they felt that family members returned to normal routines too quickly, feeling that perhaps there was not enough recognition of their vulnerable state after major surgery. Some families, on the other hand, were too eager to help and became overprotective, making it difficult for the patients to adjust to their preferred normality. Such enormous changes in the normal routine of the whole family and the impact on their social relationships were clearly apparent to patients:

Among the things I can do now that I couldn’t do before the illness is talk to my mum. While, before, we weren’t very close, I can now tell my mum anything...I’m also closer to my sister now. The whole family was shocked, my mum gave up work to be with me, and this reduced our income a lot, and my dad now works permanent nights so that he can spend the day with me. (VAD patient)

Uncertainty

In addition to seeking normality, all patients focused on feelings of uncertainty. All patients were concerned with being unable to plan for the future, worrying about their future and health and also their families’ future health and life. Patients with a VAD and explant patients worried about the possibility of developing greater heart failure in the future because of the novel clinical nature of the device and the unknown consequences of the treatment.

The worst thing about having a heart condition is the concern at the back of your mind about the future, all the unknown discussions about the lasting effects of the treatment. (Explant patient)

However, transplant patients focused on uncertainty about their longer term future and QoL:

Going home sometimes can seem a bit daunting.... I’m a little bit apprehensive about how much I’ll be able to do, how much I’ll be able to cope within the garden and the house. (Transplant patient)

Emotional State

The final conceptual category was emotional state and its ability to influence patients’ appraisal of their health or treatment plan. All patients highlighted the negative impact of uncertainty about their future health on their emotional well-being, but they also identified positive personality characteristics as important determinants of coping with uncertainty:

When you don’t know what the next treatment you’ll need is, or you receive information that is not good, your anxiety goes up but then you rationalize the situation and bring yourself down.... (Explant patient)

I’ve always had a positive outlook in life. My glass is always half full, is never half empty, you know, it’s always positive thinking with me, I’m not a negative person. It’s always getting there, so when I had to have the transplant and all that, there wasn’t fear at all.... (Transplant patient)

Although uncertainty affected the emotional state of the treatment groups differently, finding a way to live with it was a common concern for all patients. Some patients used acceptance, normalization, social support, and problem-solving strategies to help them cope with the unknown future. In some cases, uncertainty itself was used as a motivation to be more active:

One of my feelings now is apprehension because long-term, they don’t know, because they never got any track record of how things are going to turn out; we don’t know what kind of effect there will be on longevity. That’s obviously a concern at 40, although it doesn’t stop me doing the things that I would normally do, in fact it probably forces me to do more. (Explant patient)

In addition, each treatment group mentioned other concepts that were important to their emotional state. For example, the emotional state of transplant patients was particularly affected by how they coped with transplantation-related emotional issues such as receiving a donated heart from a deceased person and the unexpected mood fluctuations related to their adjustment that are common after transplantation:

After having a transplant, it was a very emotional time, up and down, up and down.... I find it quite a spooky thought having a young man’s heart inside.... It’s just learning to live with the thought that you’ve got something inside you that doesn’t belong to you. I can’t feel it physically, it’s just psychologically, in fact it is not your own heart.... (Transplant patient)

For VAD patients, their emotional state was particularly associated in the immediate postoperative period with negative emotions about receiving non-elective emergency surgery, the constant fear of the device failing, and the prospect of a long hospital stay after surgery. Factors that influenced VAD patients’ emotional recovery after discharge from hospital included having a supportive family network, the time line of the pre-VAD illness, and physical limitations.

The major downside is the operation [VAD surgery], the initial shock when you first see the pump and to see
what’s actually inside your stomach from the outside. I felt better after the initial getting used to it though. You feel like you’ve been hit by a bus after the operation, but then you just get up and carry on. Every time I thought about my kids, I thought, if I keep feeling depressed and not working towards recovering, I’m not going to see them, so that was my motivation to pick myself up and get on with it. (Explant patient)

**Identity of the Illness and the VAD**

This category was directly related to control for patients currently living with a VAD. Perceptions of control were directly influenced by the way in which patients made sense of their need for the VAD, with patients focusing on the time line of the original diagnosis, how long they had been living with the VAD in situ, and their perceptions of the consequences of a VAD on their current and future health. Patients also compared themselves with other VAD patients and with their own pre-illness health status.

The VAD is not the holy grail, it’s the quest for the holy grail rather than the grail itself, and as long as you see it like that, you see it as an interim to be at. I think it seems as an improvement to what you had before, but I think I still judge my life to what I had before my MI [myocardial infarction]. (VAD patient)

**Impact of the VAD**

Because of the specific technical and hospital requirements of living with a VAD, patients focused on experiences unique to living with this device. The impact and the identity of the VAD influenced perceptions of control in both a negative and positive way. Patients actively engaged in efforts to regain control by using coping strategies such as positive reinterpretation to reduce the amount of distress experienced.

Since I’ve had the illness, I had to give up work. It can be a bonus as you have more time to spend with your family, but it’s sometimes hard to adjust to the new life. Even though it’s a difficult situation, we both have learned to have a positive outlook and have adjusted pretty well. (VAD patient)

The patients’ perceptions of the impact of the VAD on their personal control was also influenced by the medical complications and technical factors that were common features of living with a VAD, but the negative impact of these factors on patients’ perceptions of control decreased with time as patients accepted some of the VAD-related technicalities:

…I’m pretty much in control now. I mean, I can’t do anything about when the new heart is going to arrive, and I can’t do this, and I can’t do that, but on a day-to-day basis, I’m not thinking about that, so the things that I’m not in control of are not bothering me. (VAD patient)

In particular, VAD patients identified their lack of personal independence and freedom due to the need for a 24-hour carer as a significant observable marker of reduced control over their normal routine and their general perception of control over their health.

I can’t move around as I used to, I can’t run, I can sort of do stairs now, but I need help cause that’s [batteries] really heavy, so I need someone with me all the time, and it’s a pain really, you know, you never really have time on your own, you’ve always got someone there. (VAD patient)

**Independence**

One category that was specific to all explant and transplant patients was the need for independence. Patients were specifically focused on gaining independence to maximize their adjustment and QoL and to maintain or develop control.

…not having people fussed about me all the time. Not constantly being told, don’t do this, don’t do that, you can’t do this, you can’t do that. Just being in general control of myself, being able to be out on my own and not needing a carer. (Explant patient)

Independence was related to having the freedom to do activities of daily living without being restricted by their medical regimen. Patients needed time to gain this independence and largely based their independence on comparisons to the VAD-related lifestyle they had experienced. Independence was a conceptual category directly related to control for transplant and explant patients and a subcategory of the conceptual VAD category (the impact of the VAD). This can be explained by the way in which different patient groups defined independence and its impact on control. For example, transplant and explant patients defined independence as the ability to perform daily activities without feeling overprotected by the people around them, whereas VAD patients related lack of independence to the VAD device specifically and its impact on their daily lives (see “Impact of the VAD” section).

After the operation [explantation of the VAD], you want to be independent and you feel suffocated with people around, but gradually you get your own independence. (Explant patient)

**Discussion**

This study investigated 2 research questions focusing on the construction of psychological adjustment and QoL for patients diagnosed with end-stage heart failure at 3 different stages of care (VAD, explant, and transplant). Analyses using a grounded theory framework revealed that the key core concept related to QoL was perceived control. In addition, all patients identified uncertainty, emotional state, and normality as 3 important conceptual categories directly associated with perceived control. Two conceptual
categories associated with the impact and identity of the VAD were specifically identified as relevant for VAD patients. Patients particularly identified independence as a concept directly related to control and greater, more positive adjustment after having the VAD removed.

Concepts Relating to Perceived Control

All patients concentrated upon normalizing their experiences to achieve maximum control over their current and future health. Normalization was achieved through either cognitive comparisons with others or comparisons with their pre-illness self. In addition to feelings of normality, behavior was also ranked as “normal” through its frequency and comparison with familiar pre-illness behaviors. Engaging in routine behaviors such as working or socializing improved perceptions of control. Normality was a safe, desirable state that helped patients feel in control and therefore had a positive impact on their perceived adjustment and QoL. The value of normality was clear as this conceptual category was referenced more frequently than any other category and was often referred to interchangeably with perceived control. Previous literature also identifies the importance of maintaining a normal routine for people diagnosed with other cardiac conditions.13

Heart failure and its treatment affected not only the patients’ routines but also family routines. Patients and families normalized the changes to family roles and relationships to increase their perception of control. This is also supportive of other studies that have identified the importance of families using creative strategies and being flexible in their family roles to increase perceptions of returning to “normal” during times of illness and treatment.14

Another conceptual category associated with control was their level of uncertainty. It was clear that control diminished as uncertainty increased because of changes in treatment regimen or concerns about future health. Although uncertainty was experienced by all patients, its focus changed between patient groups from short-term uncertainty (for VAD and explant patients) to more long-term health concerns (for transplant patients). Changes found in the focus of uncertainty seem related to the longevity of the surgical treatment and the timeline of the illness, which has also been identified as an important predictor of poor adjustment and QoL in a previous qualitative study with heart failure patients.15

Strategies to reduce uncertainty and increase perceived control focused on developing trust in medical professionals and gaining relevant information to familiarize themselves with the issues related to their health. These strategies were also documented by Mishel and Braden,16 who suggested that social support, credible authority, and event familiarity had the greatest influence on lowering the level of uncertainty in illness. Mishel17 also posited that event familiarity (the habitual or repetitive nature of the environment structure) promotes personal understanding and an understanding about the meaning of an event. This was apparent in this study population.

Control was also largely influenced by patients’ emotional state. A negative emotional state was largely dependent on emotional coping styles and negative personality characteristics, which also had a bidirectional relationship increasing uncertainty and reducing perceptions of normality. Previous research with heart failure and transplant patients has found that adaptive coping, acceptance, and positive reappraisal of symptoms are indicators for long term physical and psychological health.18

The Role of Illness Perceptions

Illness perceptions, and particularly perceived control, were prevalent cognitions that were important in the overall construction of QoL. In addition, the identity that patients attached to heart failure and the VAD, the attributions they associated with the cause of heart failure, the timeline they perceived was involved in their recovery, and the consequences of having heart failure were clearly related to emotional state, social well-being, and physical functioning. A theoretical framework for understanding the role of illness perceptions is the self-regulatory model, which has been used to determine how individuals represent, make sense of, and cope with the threat of illness and how they create their own models or representations of their illness.19 Previous research with cardiac patients has provided evidence for the applicability of these illness perceptions to predict facets of QoL and psychological adjustment,20,21 and this would also seem an appropriate application of this model for understanding the experience of VAD, transplant, and explant patients.

Differences in Psychological Constructs After Transplantation/Explantation

The basic core constructs were similar regardless of the surgical outcome. However, patients identified additional constructs important for their psychological well-being depending on the surgery. Whereas VAD patients focused on the identity of the heart failure and the overall impact of the VAD, explant and transplant patients focused on
retaining independence. Also, VAD patients focused on the short-term uncertainty of the VAD and their illness course, whereas a more long-term health and treatment concern was evident in non-VAD patients.

For VAD patients, their adjustment and well-being were influenced by the way the device impinged on their lives at a social (hospitalization and impact on family), physical (VAD technicalities), and psychological (coping and social support) level. These findings support earlier studies with VAD patients indicating the psychological and social effects of the device.\textsuperscript{22-26}

Both transplant and explant patients focused on independence as a measure to assess their sense of control and QoL. Patients normalized their situation and concentrated upon developing new routines to assist this process. Patients who had developed a coherent understanding of the VAD and positively interpreted changes in their health experienced reduced uncertainty and a greater perception of control. However, illness identity was different between the 2 groups of patients. Whereas transplant patients are encouraged to focus on themselves as healthy and engage in health prevention behaviors initiated by the hospital to maximize their QoL, explant patients are engaged in a difficult process of being well but at the same time having to be monitored and “treated” for an ongoing condition that has not been cured after the explantation of their device. Although they are striving for independence, they are reminded that they cannot be totally removed from the medical regimen designed to identify new signs of heart failure. This conceptual difference in illness identity was also influential in the process of normalization and developing greater control.

**Conclusion**

Our analyses are limited to a small cross-sectional sample of patients with end-stage heart failure receiving specialist surgery in a tertiary center. Furthermore, all patients in the VAD group had a first- or second-generation device in situ. Thus, caution must be taken in generalizing the findings to less severe heart failure patients or to patients with newer, continuous-flow VADs in situ, which have fewer constraints than do the pulsatile devices in terms of smaller device size, increased mechanical reliability and less device noise.\textsuperscript{27} However, there is no reason to doubt the authenticity of the core concept of control and the common conceptual categories (ie, uncertainty, emotional state, and normality) because they have been well supported by a variety of previous studies with chronic illness and cardiac patients. We consider it important to develop treatment-specific measures of adjustment in heart failure patients that include the factors identified in the present study, as current interventions are more functionally based. Further research will help explore and confirm elements of the study and any other relevant issues related to the VAD treatment, and a longitudinal prospective design looking at adjustment and QoL is necessary to understand the change in these concepts over time.

These findings support the need for healthcare professionals to understand the need for perceived control in these patients and to assist them in developing normal routines at an early stage in their treatment and over the changing course of their care. Supportive communication and information gathering to increase decision making should help to decrease uncertainty and increase perceived control. Attention to and assessment of patients’ emotional state are also pertinent. Interventions to increase control in cardiac patients have achieved positive results\textsuperscript{28} and suggest that cognitive appraisal strategies to decrease ambiguity and uncertainty about health threats and symptoms may be worthwhile targets for intervention and provide a theoretical framework for the education of professionals working with this population.\textsuperscript{29}

**Summary and Implications**

- Use of VADs is becoming increasingly widespread for patients with end-stage heart failure.
- Some patients are bridged to transplantation, whereas others demonstrate myocardial recovery and are able to have the device explanted, but little is known about the different psychological processes of adjustment for these patient groups.
- Patients with a VAD in situ or who had undergone explantation of the device or subsequent transplantation were interviewed, and a grounded theory approach was used to elicit key themes.
- All patients identified perceived control as their core category.
- Three related conceptual categories of normality, uncertainty, and emotional state were also identified by all groups.
- In addition, VAD patients identified identity of illness/VAD and the impact of the device, whereas transplant patients identified independence.
- Previously unrecognized concepts in the adjustment of patients either with a VAD in situ or who have had the device explanted or have undergone transplantation were identified in this study.
- These results provide a basis for the development of specific nursing and psychological care to support the surgical intervention of VAD implantation.
and, in particular, highlight the importance of understanding patients’ need for perceived control and facilitating its attainment.

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REFERENCES