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A picture is worth a thousand words: exploring the roles of caregivers and the home environment of ventricular assist device patients

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Aims

Caregivers of persons living with ventricular assist devices (VADs) are integrally involved in both medical and non-medical care. We sought to understand tasks caregivers perform after surgical recovery, ways the home is adapted for those tasks, and presence of home safety hazards.

Methods and results

We conducted semi-structured interviews with persons living with a VAD and their caregivers. Pictures were taken of areas in the home where: (i) caregiving activities occurred, (ii) VAD or medical supplies were kept, and (iii) home adaptations were made for VAD care. Pictures were described in written detail and analysed. A qualitative descriptive approach was used for analysis. The sample consisted of 10 dyads, with mostly spousal relationships (60%) between male patients (60%) and female caregivers (80%). Three themes were identified: (i) Evolution of Caregiving and Support: Patients gain independence, but caregivers are still needed, (ii) Adapting the Home Environment: Changes are focused on functional needs, and (iii) Hidden Dangers: Illumination of safety concerns by photographs. Assistance with bathing, driveline care, and medication management were common caregiving tasks. Most home adaptations occurred in the bathroom and bedroom including sleeping recliners, shower chairs, removable shower heads, and hanging hooks to hold VAD equipment. Safety hazards included minimal space for safe ambulation, infection risk, and home-made adaptations to the environment.

Conclusions

These findings describe key home caregiving tasks, home adaptations, and safety concerns that require further education and support. Utilizing pictures may be a feasible method for assessing VAD teaching, caregiving needs, and identifying potential risks.

Keywords

Heart assist device • Heart failure • Caregiving • Safety • Home health

Implications for practice

- Ventricular assist device (VAD) caregivers help with bathing, instrumental activities of daily living and emotional support.
- Home adaptations focused on bedrooms and bathrooms.
- Photographs of home environment may inform VAD teaching.

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Introduction

Caregivers of persons living with a ventricular assist device (VAD) must address a wide range of needs: assistance with everyday activities, transitions between settings of care, medication management and wound care.¹ New caregiving roles and tasks emerge based on the changing needs of the patient and additional responsibilities related to VAD therapy including equipment management, dressing changes and monitoring for adverse events such as infection or stroke.² However, because family caregiver contributions to VAD care are not routinely assessed in healthcare delivery or collected in registries, little is known about the context and nature of their care activities, particularly as families adjust to long-term life with the VAD.³ As the numbers of individuals receiving VADs increase, innovative means of assessment and management are needed.⁴

Caregivers often help with activities of daily living (ADLs) or the tasks required for independent self-care, including ambulation, feeding, dressing, hygiene, continence, and toileting. Caregivers are also commonly engaged in instrumental activities of daily living (IADLs), which are more complex tasks such as transportation, shopping, managing finances, meal preparation, cleaning, and managing medications.⁵ Physical functioning of VAD patients, including ADLs, is routinely assessed in clinical care. However, caregiving tasks that are performed by caregivers and unmet needs of caregivers to effectively care for the patient are not routinely assessed.

Adapting to life with a VAD occurs in four phases: pre-implantation, implant hospitalization, early home adaptation, and late home adaptation.⁶ Late home adaptation begins around 6 months post-implant and is characterized by a sense of normalcy with the long-term adjustment, but has not been a focus of observational or interventional research in VAD caregiving. Even when patients and caregivers endorse high levels of self-care confidence and caregiving preparedness upon discharge,^{1,7,8} many report encountering significant unexpected challenges in adapting to the home environment that cause substantial stress for the VAD patient-caregiver dyad.⁷ One mechanism to facilitate the transition between adaptation phases is coping through development of routines and systems that work for the dyad in the context of their relationship and home environment.⁶ However, lack of research on common care tasks and challenges within the home environment impedes the development of educational and supportive interventions to enhance long-term adjustment to VAD.

Objective

We explored the late home adaptation phase as dyads found their 'new normal' and adjusted to long term life with VAD therapy.⁶ Specifically, we sought to address the following questions: What are the tasks caregivers are doing after initial surgical recovery, and how have VAD dyads adapted the home to accomplish these tasks? Are there common safety concerns that can be identified?

Methods

Study design

We employed a cross-sectional design employing qualitative descriptive methods, using semi-structured interviews and photographs collected concurrently. This manuscript reports a research question established *a priori*. Previous analysis from this study explored dyadic congruence in managing uncertainty of living with a VAD.⁹ This study conforms with the principles outlined in the Declaration of Helsinki. Study procedures including informed consent were reviewed and approved by the Johns Hopkins School of Medicine Institutional Review Board (IRB00170548).

Sampling strategy

Persons living with a VAD and their caregivers, receiving care at the VAD clinic of a single urban academic medical centre in the eastern United States were enrolled in the study. We used purposive sampling of different types of patient and caregiver dyads in order to include a range of caregiving experiences and dyadic relationships. These dyadic types included spousal and non-spousal caregivers, male and female caregivers, caregivers who do not reside with the VAD patients but provide care at least three times per week, and a range of patient independence with VAD management.

Inclusion/exclusion criteria

Patients and primary family caregivers were included if they were: (i) 21 years or older, (ii) English speaking, and (iii) more than 3 months post-implant. Patients were excluded if they were more than 1 year post-implantation or had not been hospitalized within the past 3 months. These criteria were selected to capture patients with active caregiving needs. Patients were recruited following VAD clinic visits. Caregivers who attended VAD clinic were recruited during visits and those who did not attend visits were contacted by phone with the permission of the patient.

Data collection and analysis

We conducted semi-structured interviews in the homes of persons living with a VAD and their caregivers. Demographic and socioeconomic data were also collected to describe the sample. Interviews were conducted with patients and their caregivers separately unless the couple requested to do the interview together. Interviews took approximately 30 min per person. All interviews were conducted by female nurses; two team members had previously been engaged in care of patients (M.A.A. and N.P.). Study team members were each trained to conduct qualitative interviews by the principal investigator (M.A.A.). To build rapport each interview began with introductions and study team sharing their professional roles and interest in caregiving. Exemplar questions (see appendix) from the interview included, 'Tell me about what tasks you need help with (or for the caregiver, that you help with) and who helps you do them? How have you changed your home to support <the patient>?'. Interviews were recorded and transcribed for analysis. Interviews were conducted until data saturation occurred as determined by consensus of the study team that new data was emerging.

A working codebook was developed from multiple readings of the transcripts. We strove for coding categories generated from meaning inherent in the data rather than pre-specified categories. We created a definition for each code to ensure integrity of code use across transcripts. Team members independently coded transcripts (L.D., L.L., and M.A.A.) and suggested large subject areas (e.g. 'caregiving tasks') that were present in the interview and noted text that was not covered by existing codes. Qualitative analysis software F4analyze 2.5.2 was used.¹⁰ To ensure trustworthiness, we reviewed transcripts as a team and discussed

discrepancies to reach consensus. A qualitative descriptive approach was used, moving iteratively between codes and text to derive themes.¹¹

In addition, we collected photographic data of caregiving spaces and home adaptations. After interviews, the study team asked for a home tour. We took pictures of areas in the home where: (i) caregiving or medical activities took place, (ii) VAD or medical equipment or supplies were stored, and (iii) home adaptations to accommodate the device or VAD care was undertaken. Pictures were described in written detail (N.P. and S.B.) and treated as additional qualitative data. A priori codes ('caregiving tasks', 'home adaptations', and 'safety concerns') were used to categorize the data. Coded data from picture analysis were used to complement and enhance data obtained from interviews.

Results

Sample description

Of the 15 recruited dyads, 10 dyads completed interviews in the home. Common reasons for not completing the interview were: re-hospitalization and death ($n = 1$), withdrawal from study ($n = 1$), and lost to follow-up at the interview scheduling stage ($n = 3$). The characteristics of the patients and caregivers who completed interviews are presented in [Table 1](#). The majority of patients had their device implanted as destination therapy ($n = 7$, 70%) and were interviewed <1 year after VAD implant ($n = 8$, 80%). Patients and caregiver dyads were similar in age, usually of the same race, and most dyads were married or domestic partners. Our team identified three themes from the coded interview and photograph data ([Figure 1](#)): (i) Evolution of Caregiving and Support: Patients gain independence, but caregivers are still needed, (ii) Adapting the Home Environment: Changes are focused on functional needs, and (iii) Hidden Dangers: Illumination of safety concerns by photographs. Quotes to support themes are presented in [Table 2](#).

Evolution of Caregiving and Support: Patients gain independence, but caregivers are still needed

VAD patients and caregivers first addressed how caregiving differed in the immediate post-hospitalization phase and how ill-equipped they felt in the early transition home. Informing this theme, interviews provided historical context of tasks and the details regarding tasks, while pictures provided valuable examples of organization for tasks ([Figure 2](#)). Initial set up of VAD equipment and developing a system for medical care was extremely stressful; however, dyads said that their situation improved over time. As routines were established and the dyad coped with changes related to having the VAD, caregiving tasks were reduced and they adjusted well.

Caregivers provided minimal support for ADLs, except for help with managing the VAD while bathing; almost all caregivers ($n = 9$) reported some involvement in this task. The caregiver was typically assigned to manage the VAD while the patient cleaned themselves. Challenges of bathing were the most common frustration of VAD care, which limited the patient's independence,

'She won't let me clean up, but I mean, I have without her knowing, but I just want to get back

to doing, like I said, I like to be independent on my own'. (VAD_005_Patient)

In addition, most caregivers continuously remained involved with regular VAD dressing changes, either retaining primary responsibility for the dressing change ($n = 3$) or changing the dressing with some level of patient collaboration ($n = 3$). Four patients changed their own dressing with minimal or no assistance.

When discussing IADLs, such as cooking, household cleaning and maintenance, more differences were noted by relationship type of the dyad. Most spousal/partnered caregivers ($n = 7$, 70%) were highly engaged in IADLs. But, several described situations where the wife had always managed cooking and the household, meaning little had changed in this regard since VAD implant. Dyads that were not couples, and dyads in which the patient had more complex caregiving needs were more varied in their approach to IADLs.

Daily management of medicines and medical appointments was the most common IADL requiring caregiver support. Only two patients, both women with non-spousal caregivers, described independence with this care. In addition, most dyads talked about how complicated VAD care was and that it took two people to comprehend all of the information. This was commonly complicated by the healthcare needs of the caregiver, who themselves had healthcare concerns, appointments and medicines to manage.

'We both coordinate our cellphone's calendars... that's the only way we can keep track'. (VAD_009_Caregiver)

Finally, many caregivers felt an essential task was to foster the patient's transition to increased independence. Caregivers talked about how they supervised tasks until both the patient and the caregiver felt comfortable that the patient could be more independent. Successfully navigating these transitions created a sense of shared strength and accomplishment.

Adapting the Home Environment: Changes are focused on functional needs

When dyads gave a home tour (recorded in the interview and with pictures), most indicated multiple areas where the home was modified after VAD implantation. On average, these were minor, low-cost home adaptations. For instance, in the bathroom, common changes made included using a shower chair, installing an adjustable shower head and installing a hook for hanging the VAD shower bag. Bedroom changes varied and related to the relationship of the dyad, space constraints and the management of other co-morbidities (i.e. sleep apnoea) in both the patient and the caregiver. Sleeping arrangements included hospital beds, recliners, shared beds, and separate sleeping arrangements.

'I mean in our bedroom, we have a recliner right next to the bed so I sleep in the bed and he sleeps on the recliner so we're next to each other'. (VAD_002_Caregiver)

About half of the dyads rearranged furniture in the bedroom or changed sleeping arrangements, taking into account the ability

Table 1 Sample characteristics

	Patient (n = 10) n (%)	Caregiver (n = 10) n (%)
Age (mean ±SD), median	55.8 ± 12.8 49	52.6 ± 14 55
Gender		
Male	6 (60)	2 (20)
Female	4 (40)	8 (80)
Race		
African American	4 (40)	4 (40)
White	5 (50)	5 (50)
Asian	1 (10)	1 (10)
Implant strategy		
Bridge to transplant (BTT)	3 (30)	—
Destination therapy (DT)	7 (70)	
Time (months) since implant		
>12 months	2 (20%)	—
<12 months	8 (80%)	
Employment status		
Working now	1 (10)	2 (20)
Looking for work, unemployed	1 (10)	2 (20)
Retired	4 (40)	4 (40)
Disabled, permanently or temporarily	3 (30)	2 (20)
Homemaker	1 (10)	
Education level		
<12th grade	2 (20)	2 (20)
Graduated high school	1 (10)	1 (10)
Some college, no degree	4 (40)	3 (30)
Bachelor's degree	2 (20)	1 (10)
Graduate degree	1 (10)	2 (20)
Marital status		
Never married	2 (20)	1 (10)
Married	6 (60)	7 (70)
Widowed	1 (10)	1 (10)
Divorced	1 (10)	1 (10)
Type of home		
Rented apartment		3 (30)
Single family home		7 (70)
Number in Household (mean ± SD), median		3.2 ± 1.3, 3
Annual household income		
Less than \$14 000		1 (10)
\$14 000–\$21 999		1 (10)
\$22 000–\$35 999		2 (20)
\$49 000 or more		4 (40)
Prefer not to say		2 (20)
In general, how do your finances usually work out at the end of the month? Do you find that you usually end up with		
Some money		4 (40)
Just enough to make ends meet		4 (20)
Not enough to make ends meet		2 (20)

to walk to the bathroom while remaining attached to AC power, distance to the power outlets, and other factors. In addition, the bedroom was a common site for VAD equipment

storage, medicines and dressing change supplies. Some patients preferred to have the battery charging station within reach on a nightstand.



Full themes are: (1) Evolution of Caregiving and Support: Patients gain independence, but caregivers are still needed, (2) Adapting the home environment: Changes are focused on functional needs and (3) Hidden Dangers: Illumination of safety concerns by photographs

*ADL= Activities of Daily Living

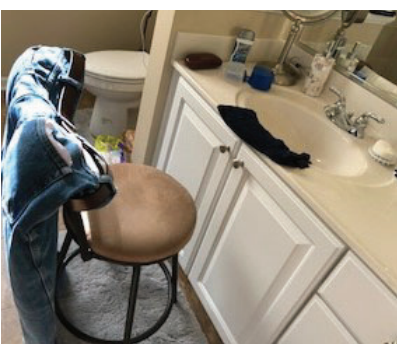

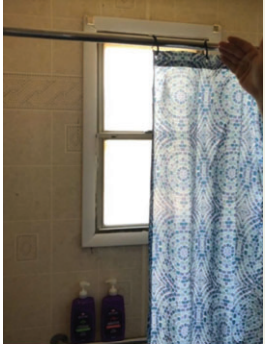


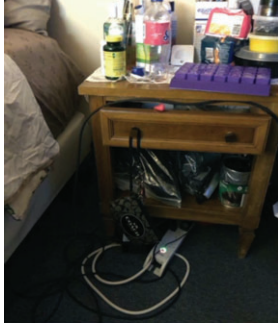
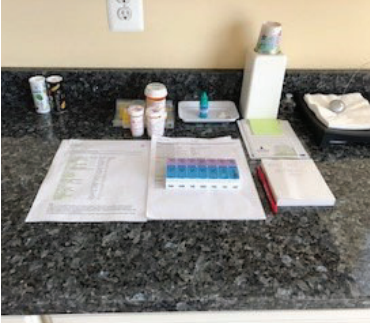


*IADL= Instrumental Activities of Daily Living

*VAD = Ventricular Assist Device

Figure 1 Qualitative coding tree. Full themes are: (i) Evolution of Caregiving and Support: Patients gain independence, but caregivers are still needed, (ii) Adapting the Home Environment: Changes are focused on functional needs, and (iii) Hidden Dangers: Illumination of safety concerns by photographs. ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; VAD, ventricular assist device.

Table 2 Representative quotes for themes

Themes	Representative quotes
Evolution of Caregiving and Support: Patients gain independence, but care-givers are still needed Bathing	<ul style="list-style-type: none"> • ‘And he needs to shower, yeah, then I help him a bit. Yeah, other than that, he’s actually fine. I just help him shower and then dressing change’. (VAD_003_Caregiver) • ‘Like I said, my mom, she washes my back because I can’t reach that, but getting dressed and stuff like that, no. She, like I said, she won’t let me clean up, but, I mean, I have without her knowing, but I just want to get back to doing, like I said, I like to be independent on my own’. (VAD_005_Patient)
IADLs	<ul style="list-style-type: none"> • ‘I do mostly like wifely duties, I guess you would say. I fix dinner and cook for him or make him something to drink or just normal things’. (VAD_009_Caregiver) • ‘Well, everything. I mean, honestly I do the outside work. I always did for the most part, but he worked long hours and stuff like that, but now it’s like if I don’t do it I have to get the boys to do it’. (VAD_010_Caregiver)
Daily management of medicine/care	<ul style="list-style-type: none"> • ‘We both coordinate our cellphone’s calendars. . . When we go to the doctor or whatever, the first thing we both do is pull out the phone, hit up the calendar and that’s the only way we can keep track. That, at first, was a tough struggle to get to that point, but now we’ve got it handled and we don’t usually miss any appointments unless it’s weather-related or something, not just because we forgot or didn’t know or something’. (VAD_009_Caregiver)
Transition to independence	<ul style="list-style-type: none"> • ‘Yeah, I want her to be more independent, so I don’t necessarily jump up to help out right away, where in the beginning [when] she came out and sat down, I stared at her <laughs> and made sure that everything was okay. Well now, not so much. “Hey, you want something to eat? Okay, well there’s the kitchen, whip it up,” and then she’s doing really great in that respect. She’s a lot more independent now, and I’m very proud of her’. (VAD_013_Caregiver) • ‘I did it until she felt comfortable enough to do it [dressing change] on her own, and we practiced a couple of times like, a couple of days before it was time for me to leave I would let her—I would watch her do it, walk her through it like they taught me here’. (VAD_015_Caregiver)
Adapting the Home Environment: Changes are focused on functional needs Bathroom	<ul style="list-style-type: none"> • ‘Hooks everywhere would be really good. That’s one thing, and then—Yeah, and then even your car, a hook just to—on your door to even make sure that when you pull the door open it doesn’t drop, because she’s seen me—with me when I’m like “Whoa”. [patient indicated he had dropped the VAD and caught it] (VAD_003_Patient)
Bedroom	<ul style="list-style-type: none"> • ‘I mean we kind of lay—I mean in our bedroom, we have a recliner right next to the bed so I sleep in the bed and he sleeps on the recliner so we’re next to each other’. (VAD_002_Caregiver) • ‘I got a certain—it’s like a—my storage, my battery storage, is set up next to the bed, but it’s right on top of, like, a little, like, a little storage bin. It’s right—everything is near the bed. Everything. So it’s like I don’t get up and got to walk this place for that because everything is right there near the bed. One on one side; one on the other side. So, I mean, like I said, everything’s convenient for me’. (VAD_005_Patient)
Organization with technology	<ul style="list-style-type: none"> • ‘Oh, yeah, Alexa comes on at 5:30 every day to remind him to take his coumadin’. (VAD_002_Caregiver) • ‘I have my timer on my phone. So when it’s 8:00 I know it’s time for me to use the morning dose. And when it’s afternoon, then the alarm on my phone will come up. And in the after—in the evening, too. So it was my baby that set it up for me. Because there was a time I missed my dose’. (VAD_004_Patient)

ROOM	PICTURES		
BATHROOM			
	<p>Stool placed in front of sink for bathing. Patient has not showered since VAD implant.</p>	<p>Hooks installed next to shower to hold VAD controller during showering.</p>	<p>Patient drapes VAD controller over unsecured shower rod during showering.</p>
BEDROOM			
	<p>Patient uses recliner for sleeping and drapes wall power cable over closet door handle to reach controller.</p>	<p>Wall power cable draped over bedframe to reach VAD in small sleeping</p>	<p>Bedside table used as multi-purpose storage space for medications and VAD cables.</p>
MEDICATIONS			
	<p>Printed full medication list and AM/PM pill box to organize daily medications stored on kitchen counter.</p>	<p>Medication pill box with Early-AM/AM/PM/EVE slots stored on bedside table.</p>	<p>Pill bottles stored in one place together in plastic storage bags.</p>

*VAD = Ventricular Assist Device

Figure 2 VAD pictures by room. VAD, ventricular assist device.

Because of the intensity of VAD equipment management, dressing changes, medication and appointment regimens, all dyads developed systems for organizing themselves in a way they were not doing prior

to the VAD. For VAD equipment, most dyads kept the charger in the bedroom or the kitchen for easy access, while the 'go-bag' of extra batteries and controller were typically kept close to the door. In one

case, a dyad used a sticky note on the door, ‘Do you need a battery?’. Central locations like the refrigerator door or kitchen counter were used to store appointment and medication information. Highly organized dyads had dedicated space for dressing changes, purchased plastic storage bins for equipment, used pill boxes and detailed systems for tracking appointments. Although each dyad used technology differently, many used technology to provide extra organization by setting reminders on phones and sharing electronic calendars. Only one dyad had a home monitoring device and relied heavily on their patient access portal to check appointments. In general, the reaction of patients and caregivers to these home adaptations focused on function. Few expressed an emotional reaction to the changes except as it pertained to sleeping separately. Of note, there were two dyads who incorporated a decorative element with VAD equipment (i.e. tablecloth and family photo) to make the device feel like part of the home.

Hidden Dangers: Illumination of safety concerns by photographs

Multiple safety concerns were noted on the home tour and picture analysis which participants did not mention in interviews (Figure 2). Across dyads’ homes, the bathroom was a common area where safety risks were apparent. A number of dyads reported hanging the VAD on unsecured objects in the bathroom while bathing. For example, two reported hanging the controller on the shower rod and the rod collapsing, causing driveline site trauma. In addition, one patient liked to set the VAD on a box next to the toilet instead of wearing it while toileting. However, the box used was cardboard and not able to be cleaned. Additionally, accessibility of cords was important but cords were draped on furniture or dropped on the floor, becoming a tripping hazard. These examples demonstrate safety concerns related to driveline trauma and risk of damage to the device and associated mechanisms. Modifications such as installed hooks or draping of cords and/or controller over rods could cause damage to the internal wiring and lead to pump malfunction. Also, potential infection risk related to cleanliness, especially near equipment, was a concern in four homes. In both homes with significant financial strain, safety concerns were noted and overcoming space limitations was a challenge from both patient and caregiver perspectives.

Discussion

In this qualitative study using home interviews and photographs, we sought to understand care tasks and home modifications that facilitated patient and caregiver adjustment to long-term life with a VAD. Our analysis revealed three themes, (i) Evolution of Caregiving and Support: Patients gain independence, but caregivers are still needed, (ii) Adapting the Home Environment: Changes are focused on functional needs, and (iii) Hidden Dangers: Illumination of safety concerns by photographs—that build upon prior work with VAD patients and caregivers. Our findings, particularly those related to safety, have important implications for patient and family education during the late home adaptation phase—a period which is not typically targeted for educational intervention, but has been identified as an area of need by both patients and clinicians.¹²

The first theme identified in this study, *Evolution of Caregiving and Support: Patients gain independence, but caregivers are still needed*—adds important contextual information surrounding the heterogeneity of care tasks and how they are distributed within the dyad in the late home adaptation phase of life with a VAD. Existing studies examining care tasks in VAD family caregiving focused on the essential activities specific to VAD management post-discharge (e.g. safely maintaining the VAD equipment, responding to emergencies, care for the driveline exit site, managing new medications, etc.).^{1,13–15} There are many other care tasks associated with heart failure (HF) caregiving that are not specific to VAD management¹⁶ and are understudied among VAD patient–caregiver dyads, including managing multiple chronic conditions and educating other providers about the VAD. With the exception of bathing, which remained problematic, care tasks were largely dictated by ADL and IADL needs that were not necessarily exclusive to VAD management (i.e. chronic illness caregiving). Furthermore, gender and relationship roles affected IADL management, leading to uneven task distributions that may create tension in the dyad. During our interviews, caregivers expressed some emotion about the tasks they performed and the home changes they needed to make in order to accommodate the VAD. Some expressed frustration about the space required for VAD equipment and supplies. Also, caregiving task description elicited emotions that seemed very tied to the nature of the dyadic relationship and/or the complexity of care. While caregiving is typically described in terms of burden, few participants expressed weariness or feelings of being overwhelmed by the tasks of caregiving. Topics that elicited the most emotional responses revolved around uncertainty and end of life planning.⁹ Fortunately, there are a number of dyadic caregiving interventions that are effective in improving both the management of disease and the health of the dyad relationship.¹⁷ One example, SHARE, is an intervention tailored to the dyad’s unique relationship context, and includes components of sustainable care task distribution.¹⁸ SHARE has undergone adaptation for HF, but not VAD, caregiving which should be tested in future research.¹⁹ Essential clinical implications from this theme are (i) the need to implement ongoing assessment of caregivers’ needs and involvement in tasks throughout VAD management, and (ii) providers should continually involve caregivers regardless of patient independence because of the complexity of VAD management.

Despite home safety being a common topic in pre-discharge teaching, there has been little examination of actual home adaptations or home safety post-implant. Effective and safe implementation of activities tailored to the patient and family’s unique environment and resources (e.g. physical and social resources) is not a standard focus of VAD education.^{1,15,20} However, safety in the home is of concern, as our photographic data revealed that home adaptations were not always safe or helpful, with unsafe adaptations not readily recognized by patients and caregivers. As such, there may be opportunities for future interventions to support overall home safety, or other minor home modifications that could promote safety and enhance independence at minimal cost.²¹ Additionally, there is a need for novel engineering solutions to provide safe, low-cost ways to extend the life of the controller and cords to promote safe functioning of the VAD.

The use of photographs to assess adaptations in the VAD home environment is a novel contribution. Pictures confirmed interview

findings for Theme 1, provided detail on changes for Theme 2, and provided information not obvious from interview data for Theme 3. Although there is precedent for using photographs in VAD patient care, images were primarily used to monitor the driveline exit site.²² There are a number of studies where photographs taken in the home were used as clinical tool. For example, photographs identified patient adaptations that were unsafe (e.g. led to medication errors),²³ were used as a tailored educational tool to support older adults' understanding of safety in the context of their environment,²⁴ and were used in an occupational health intervention to evaluate toilet-ing/bathing areas to prescribe appropriate equipment to support safety and independence.²⁵ Photo assessment to support safety in the bathroom may have particular salience for the VAD population. Bathing and toileting in the present study was a particular source of safety concerns from nurses performing interviews, but largely unrecognized concern of patients and caregivers. Bathing with a VAD has also been identified as an anxiety-inducing challenge in studies of VAD patients and caregivers.^{6,26} Although photos have not been used previously to support safe VAD patient and family adaptation to life in the home environment, the successful use of photos in this study and other studies with good inter-rater reliability^{26,27} suggests they may be a promising future tool. In addition, photos could be used for training and education purposes, suggesting successful strategies for home organization of tasks such as medication management and equipment/supply storage.

Research and clinical use of telemonitoring or televisits for VAD patients is limited, but what has been published focuses primarily on the use of digital biomarker data to support clinical stability and monitoring.^{28,29} Interprofessional team-based care 'in the home' that addresses basic safety issues and social determinants of health may be increasingly leveraged in virtual VAD care.³⁰ Clinically and in future research, home or virtual visits may provide opportunities for patients to show clinicians areas of the home where caregiving tasks occur and modifications are made, allowing clinicians to identify safety concerns and co-create solutions. Asking patients and caregivers to take pictures they share with the VAD team may also be a feasible way to increase clinician understanding of the home context, which merits further research. Moreover, further understanding of the home environment may be a useful strategy in reducing VAD complications.

Clinical implications

Our findings and prior research in this population suggest that clinicians engaged in the care of VAD patients should develop a plan for ongoing assessment of caregiver well-being and caregiving needs of the patient. It would also be beneficial for clinical teams to develop documentation processes for tracking the functional independence of the patient and ways the caregiver is involved in care over time. Increases in caregiving tasks or other caregiver responsibilities that are unsustainable (e.g. household management) could be used as a trigger for social work or palliative care referral. In addition, many programmes only provide training for caregivers at the time of implant and briefly during clinic appointments. Programmes may support patients and families better by considering a more rigorous approach to ongoing training in skills, particularly related to safe driveline care and managing bathing with the VAD. Clinician use of

pictures or even video calls may be instrumental in relieving dyad stress and supporting safety of the initial equipment set up in the home, and may also be beneficial in supporting safe, long-term home adaptations in the chronic management of the patient. Pictures of the home can also provide important insights for clinicians to prioritize teaching related to safety, medication management, ADLs/IADLs, and care of the driveline site. Ultimately, this focused teaching may improve the independence of the patient and the confidence of caregivers, but this requires further investigation.

Limitations

We also acknowledge the limitations of this study. The sampling frame limits the generalizability of our findings, poignant though they may be. Additionally, the patients and caregivers directed the home tours and identification of areas to be photographed. This leaves the potential for bias since participants told us which parts of the home should be photographed. Additional areas of the home may have been important to assess and photograph but were not identified readily by the participants. It is also likely that our semi-structured interview guide did not elicit substantive data regarding psycho/emotional response to caregiving tasks and home adaptations.

Conclusions

Caregivers and patients with VAD have ongoing caregiving needs through the late home adaptation phase of adjustment to living with a VAD. Tasks are supported by home environment adaptations, particularly in the bathroom and bedroom, and home assessment of these spaces revealed potential safety concerns. Further research focused on ongoing caregiver needs assessment and innovative evaluation of the home environment such as using remote or virtual methods may be a useful strategy in reducing VAD complications and optimizing patient outcomes.

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Data availability

The data underlying this article will be shared on reasonable request to the corresponding author.

Conflict of interest: none declared.

References

1. Casida JM, Marcuccilli L, Peters RM, Wright S. Lifestyle adjustments of adults with long-term implantable left ventricular assist devices: a phenomenologic inquiry. *Heart Lung* 2011;**40**:511–520.
2. Ben Gal T, Jaarsma T. Patients with a left ventricular assist device: the new chronic patient in cardiology. *Eur J Cardiovasc Nurs* 2012;**11**:378–379.
3. Magid M, Jones J, Allen LA, McIvannan CK, Magid K, Thompson JS, Matlock DD. The perceptions of important elements of caregiving for a left ventricular assist device patient: a qualitative meta-synthesis. *J Cardiovasc Nurs* 2016;**31**:215–225.

4. Nelson K. It takes a village to care for the mechanical circulatory support device patient throughout the care environment. *Heart Lung* 2020;**49**:220.
5. Hopkins RO, Suchyta MR, Kamdar BB, Darowski E, Jackson JC, Needham DM. Instrumental activities of daily living after critical illness: a systematic review. *Ann Am Thorac Soc* 2017;**14**:1332–1343.
6. Abshire M, Prichard R, Cajita M, DiGiacomo M, Dennison Himmelfarb C. Adaptation and coping in patients living with an LVAD: a metasynthesis. *Heart Lung* 2016;**45**:397–405.
7. Birriel B, Alonso W, Kitko LA, Hupcey JE. Family caregiver-reported outcomes regarding decision-making for left ventricular assist device implantation. *Heart Lung* 2019;doi:10.1016/j.hrtlng.2019.03.002.
8. Casida JM, Combs P, Pavol MKay, Hickey KT. Ready, set, go: how patients and caregivers are prepared for self-management of an implantable ventricular assist device. *ASAIO J* 2018;**64**:e151–e155.
9. DeGroot L, Bidwell JT, Peeler AC, Larsen LT, Davidson PM, Abshire MA. "Talking around it": a qualitative study exploring dyadic congruence in managing the uncertainty of living with a ventricular assist device. *J Cardiovasc Nurs* 2021; **36**:229–237.
10. Dresing T, Pehl T, Schmieder C. *Manual (on) Transcription. Transcription Conventions, Software Guides and Practical Hints for Qualitative Researchers*, 3rd English ed. Marburg, Germany: SAGE, 2015.
11. Flick U. *An Introduction to Qualitative Research*. London, UK: SAGE Publications, 2009, p528.
12. Barsuk JH, Cohen ER, Harap RS, Grady KL, Wilcox JE, Shanklin KB, Wayne DB, Cameron KA. Patient, caregiver, and clinician perceptions of ventricular assist device self-care education inform the development of a simulation-based mastery learning curriculum. *J Cardiovasc Nurs* 2020;**35**:54–65.
13. Marcuccilli L, Casida JM. From insiders' perspectives: adjusting to caregiving for patients with left ventricular assist devices. *Progr Transplant* 2011;**21**:137–143.
14. Magid M, Jones J, Allen L, McIlvennan CK, Magid K, Thompson JS, Matlock DD. The perceptions of important elements of caregiving for a left ventricular assist device patient. *J Cardiovasc Nurs* 2015;doi:10.1097/JCN.0000000000000242.
15. Kato N, Jaarsma T, Ben Gal T. Learning self-care after left ventricular assist device implantation. *Curr Heart Fail Rep* 2014;**11**:290–298.
16. Kitko L, McIlvennan CK, Bidwell JT, Dionne-Odom JN, Dunlay SM, Lewis LM, Meadows G, Sattler ELP, Schulz R, Strömberg A; On behalf of the American Heart Association Council on Cardiovascular and Stroke Nursing; Council on Quality of Care and Outcomes Research; Council on Clinical Cardiology; and Council on Lifestyle and Cardiometabolic Health. Family caregiving for individuals with heart failure: a scientific statement from the American Heart Association. *Circulation* 2020;**141**:e864–e878.
17. Martire LM, Helgeson VS. Close relationships and the management of chronic illness: associations and interventions. *Am Psychol* 2017;**72**:601–612.
18. Whitlatch CJ, Heid AR, Femia EE, Orsulic-Jeras S, Szabo S, Zarit SH. The Support, Health, Activities, Resources, and Education program for early stage dementia: results from a randomized controlled trial. *Dementia* 2019;**18**: 2122–2139.
19. Sebern MD, Sulemanjee N, Sebern MJ, Garnier-Villarreal M, Whitlatch CJ. Does an intervention designed to improve self-management, social support and awareness of palliative-care address needs of persons with heart failure, family caregivers and clinicians? *J Clin Nurs* 2018;**27**:e643–e657.
20. Widmar SB, Dietrich CCRN, Minnick AF. How self-care education in ventricular assist device programs is organized and provided: a national study. *Heart Lung* 2014;**43**:25–31.
21. Szanton SL, Leff B, Wolff JL, Roberts L, Gitlin LN. Home-based care program reduces disability and promotes aging in place. *Health Affairs* 2016;**35**:1558–1563.
22. Kusne S, Mooney M, Danziger-Isakov L, Kaan A, Lund LH, Lyster H, Wiesenthaler G, Aslam S, Cagliostro B, Chen J, Combs P, Cochran A, Conway J, Cowger J, Frigerio M, Gellatly R, Grossi P, Gustafsson F, Hannan M, Lorts A, Martin S, Pinney S, Silveira FP, Schubert S, Schueler S, Strueber M, Uriel N, Wrightson N, Zabner R, Huprikar S. An ISHLT consensus document for prevention and management strategies for mechanical circulatory support infection. *J Heart Lung Transplant* 2017;**36**:1137–1153.
23. Mickelson RS, Willis M, Holden RJ. Medication-related cognitive artifacts used by older adults with heart failure. *Health Policy Technol* 2015;**4**:387–398.
24. Breeden LE. Occupational therapy home safety intervention via telehealth. *Int J Telerehabil* 2016;**8**:29–40.
25. Sim S, Barr CJ, George S. Comparison of equipment prescriptions in the toilet/bathroom by occupational therapists using home visits and digital photos, for patients in rehabilitation. *Aust Occup Ther J* 2015;**62**:132–140.
26. Lehna C, Twyman S, Myers J. Using photographic interpretation to evaluate the safety of home environments. *Prev Med Rep* 2016;**4**:459–462.
27. Ritchey KC, Meyer D, Ice GH. Non-therapist identification of falling hazards in older adult homes using digital photography. *Prev Med Rep* 2015;**2**:794–797.
28. Reiss N, Schmidt T, Boeckelmann M, Schulte-Eistrup S, Hoffmann J-D, Feldmann C, Schmitto JD. Telemonitoring of left-ventricular assist device patients—current status and future challenges. *J Thorac Dis* 2018;**10**:S1794–S1801.
29. Schmidt T, Mewes P, Hoffmann J-D, Müller-von Aschwege F, Glitza JI, Schmitto JD, Schulte-Eistrup S, Sindermann JR, Reiss N. Improved aftercare in LVAD patients: development and feasibility of a smartphone application as a first step for telemonitoring. *Artif Organs* 2020;**44**:248–256.
30. Daniel H, Bornstein SS, Kane GC; Health and Public Policy Committee of the American College of Physicians. Addressing social determinants to improve patient care and promote health equity: An American college of physicians position paper. *Ann Intern Med* 2018;**168**:577–578.