Cascading Mentorship: Designing a Support Tool for Patients with Ventricular Assist Devices

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A ventricular assist device (VAD) is a surgically implanted mechanical pump attached to the heart to assist its function in patients with advanced heart failure. This paper investigates the current state of training being provided to VAD patients and caregivers, and whether it adequately prepares them for the VAD lifestyle. The study consisted of a literature review, a content analysis and interviews conducted with stakeholder representatives. A co-design process led to the development of a holistic interactive prototype that was evaluated by one VAD caregiver, one VAD biomedical engineer, and one VAD surgeon. Four key themes emerged from the research examining the VAD patient and caregiver training experience: (i) uncertainty, (ii) misinformation, (iii) gratitude, and (iv) preparation. Five overarching themes emerged as design recommendations: (1) artificial onboarding, (2) contextual empathy, (3) ongoing support, (4) physician connectivity, and (5) emergency scenarios. Findings suggest the need to focus on not just the patient, but equally on the VAD caregiver. Design opportunities include the optimisation of both training tools and VAD communication relating to emergency scenario preparation.

Medical Design; Patient Relationships; Patient-centric Design; VAD Caregiver.
1 Introduction

Chronic heart failure is a complex and widespread disease, affecting an estimated 300,000 Australians (National Heart Foundation of Australia, 2011), with another 30,000 new cases diagnosed each year (Australian Institute of Health and Welfare, 2011; Sahle, Owen, Mutowo, Krum, & Reid, 2016). There were over 167,000 hospitalisations where heart failure and cardiomyopathy was recorded as either the principal or secondary diagnosis which represented 1.6% of all hospital admissions during 2014–15 (Australian Institute of Health and Welfare, 2016). A ventricular assist device (VAD) is a surgically implanted mechanical pump attached to the heart to assist its function in patients with advanced heart failure, saving and extending the recipients life for 5-10 years (Boyle et al., 2009) or possibly more (Gustafsson & G.Rogers, 2017) while they wait for an available donor.

In addition to the implanted VAD pump, there are a number of additional external components that require constant monitoring and maintenance to ensure its proper function, including the controller (Figure 1) and external battery pack. These are connected to the pump via a driveline that extends from the internal VAD through an exit site on the patient’s abdomen.

![Ventricular Assist Device (VAD) and controller](image taken by author)

While this technology is revolutionary and lifesaving (Starling, 2010), it has a significant impact on the patient’s and caregiver’s quality of life as it places a number of limitations that can burden those who rely on the device (Jessie Casida, 2005; Muldoon, Barger, Flory, & Manuck, 1998). Daily activities such as showering, eating, exercise and sleeping can become complicated with the extra VAD management required (Starling, 2010).

Successful medical device development requires various input from many different disciplines, such as industrial design, engineering, clinical, regulatory, marketing, sales and business expertise (Privitera, Southee, & Evans, 2015) to design and deliver not only the artefact itself but also the ongoing user interaction surrounding a device and the system and environment it exists within. The role of the designer here is often that of user advocate, providing insight and opinion (Privitera et al., 2015), as well as aesthetic design, form giving, human factors application and testing, along with contextual inquiry/ethnography methods (Petrie, Aidan; Copeland, 2011).

The aim of the current study was to better understand and gain insight into the existing state of training and preparation for VAD stakeholders, primarily the patient and their caregivers, and then to design and evaluate a design-led solution with these stakeholders. User issues with the VAD journey were identified and explored using a design process. The research findings uncovered the need to focus on not just the patient, but equally on the VAD caregiver and the opportunities surrounding both these stakeholders, and others.
In addition, the authors have attempted to improve the VAD user experience using a design process to explore the potential re-design of patient and caregiver training from the insights revealed in the research findings. The research suggests that alarms and emergency scenarios are a critical concern for patients and caregivers, as they provide a major point-of-failure of use-errors. This was identified through primary and secondary data, as well as through creation and evaluation of a prototype which supported better training through a design innovation approach.

Through this design innovation process the authors investigated the daily lives of VAD patients and caregivers once they had left hospital care, to determine whether the training received adequately prepared them to physically and mentally maintain the device. This process uncovered a set of design considerations aiming to improve the patient experience, facilitate collective resilience in the relationship between patient and caregiver, promote responsible independence, and improve the communication to clinicians.

2 The VAD Experience

2.1 Treatment Paths

VADs are utilised in four primary treatment paths for patients suffering from acute heart failure (Boling, Hart, Okoli, & Halcomb, 2015; Jakovljevic et al., 2017; Kaan, Young, Cockell, & Mackay, 2010; Makdisi, Makdisi, & Bittner, 2017; McLarty, 2015; Prinzing et al., 2016; van Manen, 2017):

- **Bridge to transplant** in which it aims to keep the patient alive by taking over (or partially taking over) the pump function of the heart while waiting for a donor heart.
- **Destination therapy** where the patient is not eligible for a transplant, a VAD is implanted as a long-term solution. They can however be re-listed for transplant if they become eligible while on VAD treatment.
- **Bridge to recovery**, used to support the heart until it recovers enough function for the VAD to be removed without transplant.
- **Bridge to decision**, where the patient condition is unstable or uncertain, a VAD implant can ‘buy time’ until a more informed decision can be made regarding transplant or otherwise

Once all other treatment options are exhausted, patients who suffer from late-stage heart failure could be considered for VAD implantation by their physicians and frequently they have very little time before the implant window closes (Yang, Zimmerman, Steinfeld, Carey, & Antaki, 2016). At this time, they are hospitalised and bedridden; often with feelings of uncertainty and fear for their future (Hallas, Banner, & Wray, 2009) as they are informed of the challenging treatment pathway ahead of them, with the genuine possibility that this treatment will continue until their death.

After they recover from their invasive VAD implant surgery the patient remains under intensive care for a number of days, before they are recommended to go through an extensive 4-6 week rehabilitation(Jakovljevic et al., 2014)(Jakovljevic et al., 2014)(Jakovljevic et al., 2014)(Jakovljevic et al., 2014)(Jakovljevic et al., 2014) and training process on how to care for and maintain this device (Jakovljevic et al., 2014; Wilson, Givertz, Stewart, & Mudge, 2009). Family and caregivers also experience the severe emotional burden (Casida, 2005) of the VAD implantation and lifestyle adaptations (Starling, 2010), as all VAD patients are required to have a caregiver to be there with them at every step of the journey. The caregiver’s role is full-time so the carer must adapt to the jarring lifestyle impacts the VAD treatment can have (Kaan et al., 2010).

2.2 Stakeholders

There are a variety of stakeholders to consider when designing for VAD treatment. Here we categorise these stakeholders as users, direct stakeholders, and indirect stakeholders in order to understand the greater context of those within this problem space.
• **Users - Patient:** the patient is someone who has received a VAD as treatment for heart failure, and is now having to adapt their lifestyle to accommodate the changes associated with VAD implantation (Marcuccilli, Casida, & Peters, 2013; Starling, 2010).

• **Users - Caregiver:** the caregiver is a family member, spouse, or friend that has elected to be the primary carer of the patient. They must receive training on how to use and maintain the patient’s VAD, clean the driveline site, ensure medication is taken, ensure the patient adheres to dietary guidelines, as well as be there emotionally for the patient to provide support (Jessie Casida, 2005; Kaan et al., 2010).

• **Direct stakeholders:** Physicians are the primary point of medical contact for patients and/or caregivers, with regularly scheduled meetings and check-ups designed to ensure that the patient’s VAD is operating as expected. Nurses play a role in VAD implantation and end-of-life decision making, which can lead to strong emotional relationships being projected onto the nurses by patients and caregivers (Gibson, Henderson, Jillings, & Kaan, 2013).

• **Indirect stakeholders:** suppliers/manufacturers etc.

### 2.3 The User Experience

The training process for the patient and caregiver is fundamental to ensure prolonged device function, which allows a smooth transition from the hospital to a home environment (Wilson et al., 2009). It is obvious leaving patients and caregivers potentially unprepared and at risk of making errors in situations that could mean life or death. Even something as simple as ongoing care of the driveline exit site to minimize the risk of infection can benefit from education tailored to patients and caregivers (Barber & Leslie, 2015). However, VAD training is currently limited, inconsistent between institutions nationally and internationally, and restricted to VAD-equipped hospitals and medical staff (J. M. Casida, Aikens, Craddock, Aldrich, & Pagani, 2017; Jesus Casida, 2017; Hawkins, Fynn-Thompson, et al., 2017; Hawkins, Ventresco, & VanderPluym, 2017).

Existing research (Gibson et al., 2013) has explored the experience of nurses who primarily deal with VAD patients and revealed the complexities that emerge from direct exposure to these patients, such as developing exclusive professional knowledge that is not always valued or best utilised, forming emotional connections with patients who will inevitably pass away at some stage, witnessing adverse events, and dealing with the uncertainty of “second chances” along with the nuances of human experience.

The study also highlights the anxiety, loss, pressure, and emotional stress that family caregivers go through, highlighting the VAD implant journey can be more stressful and difficult for family caregivers than for patients. In fact, there is evidence that VAD caregivers suffer higher rates of Post-Traumatic Stress Disorder than VAD patients themselves (B. Bunzel, Laederach-Hofmann, Wieselthaler, Roethy, & Drees, 2005; Brigitta Bunzel, Laederach-Hofmann, Wieselthaler, Roethy, & Wolner, 2007; Kaan et al., 2010). Moreover, a study by Chapman, Parameshwar, Jenkins, Large, & Tsui (2007) explored the impacts that VAD treatment can have on the patient’s physical and psychological wellbeing, highlighting significant issues such as patients and their families needing additional psychological and emotional support during and after use of a VAD, and that assessment before implantation of a VAD can sometimes reveal the need for additional support.

A decision support tool is one solution to assist practitioners in making the right choice for VAD implantation. A study by Yang, Zimmerman, Steinfield, Carey, & Antaki (2016) revealed a lack of perceived need and trust for machine intelligence by physicians for VAD decision support tools. However, the research suggested that the use of machine intelligence could help with clarifying and monitoring of a patient’s condition as well as managing decisions to escalate treatment. The study was focused on the impact that design-led decision support tools could have on the clinical decision process around VAD implants, as well as attempting to identify key ways to seamlessly integrate
these tools into the clinician’s work so that they would be more willingly accepted (Yang et al., 2016).

2.4 Current VAD Training Resources

Patients and caregivers undergo an essential training process to prepare for post-hospital life. They must be able to understand the care of drivelines and demonstrate competency in performing daily self-care routines such as sterile dressing management using disinfectant, masks, and sterile gloves with competency testing by physicians (Englert, Davis, & Krim, 2016). Commonly, the resource that patients and caregivers are provided with takes the form of an information pack which can vary between medical institution and VAD manufacturer, with the curation of this pack being at their physician's discretion (Figure 2).

Figure 2 Example resources provided in information pack for training and VAD essentials for home use

In addition, there are both theoretical and practical proficiency tests that are prerequisite for both patient and carer to complete in order to meet their physicians’ standard before discharge from hospital, as well as Flow Sheets (i.e., physical forms that patients and caregivers are required to fill out to track a number of critical daily maintenance tasks and VAD controller data). These are delivered at regular scheduled hospital visits for physicians to be able to track and monitor device function.

3 Methods

For the purposes of this research exploring the issues relating to VAD patient and caregiver training, an iterative user-centered design process was utilized to identify and overcome some of the issues raised. This research design process consisted of the following stages: (1) content analysis of current digital VAD training and resource platforms; (2) identification of user requirements; (3) prototyping and co-design of a training solution concept.

3.1 Stage 1: Content Analysis

A qualitative content analysis (Nusem, Wrigley, & Matthews, 2017; Straker, Wrigley, & Rosemann, 2015) of existing digital platforms was performed in order to gain a greater understanding of the existing VAD solution landscape. The purpose of this was to identify the standards with current VAD solutions, as well as to detect gaps within the market for potential opportunities. Thus, digital platforms were selected for inclusion based on providing benefit to VAD patients and/or their caregivers specifically. Platforms that were unreleased or did not have an interactive demo available to the authors were excluded.
Three digital platforms were selected – VADable App, CORA Patient Counsellor and MyLVAD – as exemplars due to their search ranking and/or recurrence in results within various search terms. For the selected digital platforms, key strengths and weaknesses were assessed and general observations about the usability of the platforms were included based on the perspective of a VAD patient (Tsiouris et al., 2015).

3.2 Stage 2: Identification of user requirements

A literature review was conducted to gain an insight into the current VAD user experience, with a focus on patient usability and patient experience. Insights gathered from the existing literature were processed through several user empathy methods during Stage 2 in order to visualise, translate and summarise the research findings as well as provide reference material to ensure any derived solution could be re-evaluated against the user research. These include personas, journey mapping, affinity diagramming, and extreme persona-based scenarios. Findings from Stage 2 informed the third stage: prototyping and co-design.

Personas

Personas are archetypal representations of the target stakeholders that are formed out of the insights and themes uncovered from user research. They provide an empathetic point of reference for assessing the value of concepts, as well as providing various unique perspectives that can be utilised when evaluating with role-playing and scenario walkthrough methods (Pruitt & Adlin, 2010). VAD patient and caregiver personas (Appendix A) were developed to visualise and characterise the insights gathered from user research empathetically.

Journey Mapping

Journey mapping is the process of visualising all aspects of the user experience to provide a holistic representation of the current interactions and pain points, for example points of friction within a solution or service that have an adverse effect on the experience of the user (Nenonen, Rasila, & Junnonen, 2008; Wrigley, 2013). Developing a user journey map provided a sense of empathy and understanding of the number of touchpoints (a digital or physical point of interaction with a solution or service) and detailed experiences of a patient undergoing the VAD surgery and recovery process; which allows for the discovery of gaps that could lead to potential opportunities for design-led solutions. Moreover, it can also be used as a point of reference for evaluating concepts and solutions to ensure that all aspects of the patient experience are considered.

To identify key pain points for different stakeholders, the VAD experience was mapped into six distinct phases including, Introduction, Surgery, Recovery, Adapting, Living and End of Treatment. Results revealed a deeper understanding of the contextual issues surrounding VAD patients and their caregivers, while also uncovering key issues and identifying possible opportunities for the design of a training tool (Appendix B).

Affinity Diagramming

Affinity diagramming was utilised as a process to facilitate refining and synthesising a broad range of user data from various research methods into clear patterns and groupings (Holtzblatt, Wendell J. B, & Wood, 2005). A number of trends were discovered during this process, which were written from the perspective of the user in order to maximise empathy.

Extreme Persona Based Scenarios

An extreme persona, who is not a direct user of the product, was developed around a caregiver whose own child had undergone VAD treatment. This persona was developed with the aim of eliciting a strong sense of empathy within research participants which include dialogue techniques, narratives and imagination (Krüger et al., 2017). This encouraged participants to shift their mindset significantly and engage with the prototype through an entirely different lens of user needs and stakeholder goals.
3.3 Stage 3: Prototyping and Co-design
Stage 3 involved a prototyping and co-design session with one VAD caregiver and one biomedical VAD engineer. Prior to the workshop, and in order to inform workshop questions, a range of design resources had been developed including Personas (Appendix A) and Journey Maps (Appendix B). Participants in the co-design and prototyping session were prompted by questions by the researchers, and the workshop concluded with a participant evaluation of an initial prototype. Data were captured by a research assistant taking observation notes, photographs, and audio recording with consent. These recordings and observation notes were evaluated using thematic analysis to inform prototype iteration as well as to validate a tangible concept with these stakeholders. In addition to these tools, an initial prototype was developed of an interactive training platform designed to empower and train caregivers to in turn teach their VAD patients.

4 Findings
The aim of this study was to gain insight into the current state of training and preparation for VAD stakeholders, primarily the patient and their caregivers, as well as improve the VAD training process for patients and caregivers. The focus of this study became on the adaptation stage, which was indicated to be a critical phase for the caregiver as they are coming to terms with being responsible for the patient’s well-being, while having to follow a strict regime to protect the function of the device.

A content analysis (Table 1) was conducted on three existing VAD lifestyle solutions included VADable, MyCORA (2017) patient counsellor and MyLVAD (2017). All three solutions were digital in nature, ranging from a mobile application, to a website-based service to an online community and resource hub. However, a number of gaps were exposed:

- No real-time assistance in emergency scenarios.
- Only provided in certain stages of VAD journey e.g. decision-making stage.
- Unintuitive interfaces e.g. limited accessibility considerations, despite the mean age of a VAD recipient being 59 as determined by Tsiouris et al. (Tsiouris et al., 2015).
- Tone of communication e.g. confrontations about mortality, delivering of negative results.

<table>
<thead>
<tr>
<th>Description</th>
<th>VADable App</th>
<th>CORA Patient Counsellor</th>
<th>MyLVAD</th>
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</thead>
<tbody>
<tr>
<td><strong>Description</strong></td>
<td>VADable is a digital platform that the patient inputs daily information relating to the function of their VAD, much like the pen and paper flow sheet typically in use with VAD patients.</td>
<td>CORA is a service designed for both patients and physicians in order to assist the decision for VAD therapy in cases of advanced heart failure, as well as provide a few supplementary resources for post-surgery life.</td>
<td>MyLVAD is an online community and resource hub for LVAD patients and their loved ones. It provides a variety of information on VAD topics, with a primary focus on what to expect when living with this device.</td>
</tr>
<tr>
<td><strong>Strengths</strong></td>
<td>Daily collection of data for VAD team.</td>
<td>Variety informative videos explaining the LVAD, the surgery, &amp; testimonials from patients.</td>
<td>Introductory articles on what to expect with the VAD journey</td>
</tr>
<tr>
<td></td>
<td>Integrates with iPhone built-in health metrics by syncing with Health app</td>
<td>Interactive tools to determine whether an LVAD is right for you</td>
<td>Community forum for users to discuss living with a VAD, as well as sharing tips and asking</td>
</tr>
</tbody>
</table>
Following the content analysis, a literature review (Table 2) highlighted existing research in the field of VAD user experience, showcasing a number of important themes that were prevalent for a variety of VAD stakeholders, with a focus on patients, caregivers, and physicians. There was a common thread in a number of these studies that evaluated the ability for patients and caregivers to respond in emergency scenarios with a focus on the communication from the VAD controller visual interfaces and auditory alarms. The research insights highlighted the emotional burden of being a caregiver for a VAD recipient as well as identifying the current training and monitoring approach for VAD implantation. Four key themes (further detailed in Table 3) emerged from the research examining the VAD patient and caregiver training experience: (i) uncertainty, (ii) misinformation, (iii) gratitude, and (iv) preparation.

Table 2: Findings from literature review

<table>
<thead>
<tr>
<th>Literature</th>
<th>Description</th>
<th>Literature Findings</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing Patients with Ventricular Assist Devices: An Interpretive Description</td>
<td>This study explores the experience of the nurses who primarily deal with VAD patients, and the complexities that derive from direct exposure to these patients.</td>
<td>The experience of the VAD implant can be more stressful and difficult for family caregivers than for patients</td>
<td>Gibson, et al. (2013)</td>
</tr>
<tr>
<td>Investigating the Heart Pump Implant Decision Process: Opportunities for Decision Support Tools to Help</td>
<td>This study is focused on the impact that Decision Support Tools could have on the clinical decision process around VAD implants, as well as attempting to identify key ways to seamlessly integrate these tools into the clinician’s workflow.</td>
<td>When clarifying and monitoring patient condition as well as managing care escalation, machine intelligence can and should help</td>
<td>Yang et al. (2016)</td>
</tr>
<tr>
<td>Psychological Issues for Patients With Ventricular Assist Devices</td>
<td>This study explores the impacts that VAD treatment can have on the patient’s mind and body.</td>
<td>Some patients and their families need additional psychological support during and after use of a VAD.</td>
<td>Chapman, Parameshwar, Jenkins, Large, &amp; Tsui (2007)</td>
</tr>
<tr>
<td>Beyond the VAD: Human Factors</td>
<td>This study investigates the need for user-centered design approaches to medical device</td>
<td>An important aspect of VAD development is the usability of the device from implantation to patient discharge from the hospital.</td>
<td>Throckmorton, Patel-Raman, Fox, &amp; Bass,</td>
</tr>
</tbody>
</table>
Building on the insights gained in Stage 1 and Stage 2 of the research, in Stage 3 the scope of the prototype design and development focused primarily on training a VAD caregiver in the proficiencies of VAD alarms, while progressively testing their competency as they advanced. This prototype included a digital interface as well as a physical wearable that provided dynamic auditory and visual representations of the alarms that the participants were learning about as part of a holistic and tangible training experience. Results highlighted that the current training process for VAD users is focused on the patient, however, it is the caregiver who is responsible for the ongoing support and medical treatment of the patient. With the scope of the prototype being focused on the training and preparation for emergency scenario response competency, a number of insights specific to alarm scenarios were uncovered. Table 3 details the user requirements and themes associated with the results.

Table 3 The four key themes emerging from the VAD patient and caregiver training experience

<table>
<thead>
<tr>
<th>User</th>
<th>Requirements</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indirect Stakeholders</td>
<td>Training availability for ambulance workers</td>
<td>Misinformation (ii)</td>
</tr>
<tr>
<td></td>
<td>Automate flow sheets to minimise manual data entry by patients</td>
<td>Misinformation (ii)</td>
</tr>
<tr>
<td></td>
<td>Patient confidentiality</td>
<td>Preparation (iv)</td>
</tr>
<tr>
<td></td>
<td>Greater understanding of the patient’s home life</td>
<td>Preparation (iv)</td>
</tr>
<tr>
<td>VAD Caregiver</td>
<td>Remote digital connectivity to physicians</td>
<td>Gratitude (iii)</td>
</tr>
<tr>
<td></td>
<td>High fidelity visuals of procedures and components</td>
<td>Uncertainty (i)</td>
</tr>
<tr>
<td></td>
<td>Streamlined, actionable information during emergency scenarios</td>
<td>Preparation (iv)</td>
</tr>
<tr>
<td></td>
<td>Interfaces and information needs to meet accessibility guidelines</td>
<td>Misinformation (ii)</td>
</tr>
<tr>
<td></td>
<td>Recurring proficiency tests to refresh knowledge and ensure competency</td>
<td>Preparation (iv)</td>
</tr>
</tbody>
</table>
5 Discussion

Further to the research findings above, a number of overarching themes emerged as design recommendations to consider when shaping the design development of a patient/caregiver training tool. These were: (1) artificial onboarding, (2) contextual empathy, (3) ongoing support, (4) physician connectivity, and (5) emergency scenarios.

5.1 Artificial Onboarding

While the VAD is revolutionary in its ability to prolong the life of end-stage heart failure patients while allowing them to maintain a somewhat active, albeit restricted, lifestyle, it requires both patient and caregiver to learn critical proficiencies and knowledge in a rapid timeframe.

This VAD ‘crash course’ occurs once the patient has been deemed fit to begin rehabilitation, which can be a very traumatic time as they come to terms with this foreign device. This can impact the abilities of both patient and caregiver to retain information (B. Bunzel et al., 2005; Brigitta Bunzel et al., 2007). Reports of life-threatening situations due to misunderstanding of procedures are well-known within the field of VADs but have often been attributed to clumsiness of users or caregivers (Geidl et al., 2011).

While some research (Geidl et al., 2011) indicated that simulating the VAD lifestyle for patients prior to surgery would help lessen the jarring impact of the device as part of an onboarding process, additional research highlighted that this would be impossible for the patient due to them being hospitalized and bedridden with end stage heart failure, as well as the fact that there is usually a very short time frame between physicians deciding on VAD treatment and the VAD being implanted (Friedman & McMahon, 2014; Yang et al., 2016).

Therefore, simulation training tools (Hawkins, Fynn-Thompson, et al., 2017; Hawkins, Ventresco, et al., 2017) would have the greatest benefit for caregiver, and would allow them to build their proficiencies while the patient is undergoing surgery or in ICU. This would allow the caregiver to become the patient’s mentor when they are ready to begin their training and rehabilitation.

5.2 Contextual Empathy

In response to the user challenges described throughout this paper, the authors created and tested a holistic, interactive training tool designed to simulate the tangible experience of wearing and maintaining a VAD (Figure 3 and Figure 4). This design solution was intended to prepare the caregiver from the VAD patient’s perspective, providing a level of contextual empathy. That is, the experience of using and wearing the training tool was designed to help caregivers to empathetically understand the psychological impact of VAD treatment during everyday life, in addition to surgical, technical, and hygienic aspects (Schima et al., 2014). Everyday life with a VAD can be complicated by: unintentional dropping of the controller and battery pack bag, disconnection of cables leading to pump stop, discomfort from wearing the accessory bag, handling of alarms, and the need to have a confident fail-safe action in emergency situations (Schima et al., 2014).
5.3 Ongoing Support
In this study, an analysis of existing VAD support solutions highlighted many gaps in the market landscape. While the each of the solutions that were explored had their own purpose and specific issues that they were addressing, patients and caregivers would need to maintain and use a number of these solutions over the course of their VAD treatment.

Findings indicate a need for an end-to-end solution that can train the caregiver (and by proxy the patient) as well as provide ongoing support in maintaining the daily routines and tasks that are frequent along the VAD journey. A standardisation of alarms, labels, connectors, and international guidelines for VAD patient management could potentially optimise the clinical outcome and improve patient safety and satisfaction (Schima et al., 2014; Schöglhofer & Schima, 2018).

5.4 Physician Connectivity
In addition, both the VAD caregiver and physician interviewed expressed a desire for a level of remote digital connectivity to minimise face-to-face visits when there was an uncertainty or a perceived complication - especially in relation to providing Flow Sheet data and potential infections discovered when cleaning the patient exit site (see Figure 5). The caregiver expressed that they would frequently email their physician photos of the exit site to get their professional opinion on whether treatment was required.
Similar remote connectivity functionality was present in one of the analysed existing digital support tools, VADable, a ResearchKit study app launched by the USC Keck School of Medicine’s Cardiology Department. VADable facilitates the sending of daily Flow Sheet information (pump speed, pump flow, pulsatility index, power) to a patient’s physician.

![Image](image.jpg)

**Figure 5** Simulating remote medical connectivity functionality of physician exit-site infection diagnosis

### 5.5 Emergency Scenarios

A prevalent concern for VAD patients and caregivers was that of alarms, and controller faults in the event of an emergency scenario, with Schima et al. (2014) finding in their study that only 13% of the elderly felt safe in connection with emergency situations (by contrast, 47% in the 20–30 years group). In these scenarios, it is crucial for VAD patients and caregivers to be adequately prepared to identify and address the issue. Misunderstanding of procedures (Geidl et al., 2011) to prevent a potentially fatal outcome can be attributed in part to a user misunderstanding the communication of an event or issue from the device itself. The experience of addressing an issue in practice can be much more traumatic and stressful than learning theoretically in a simulated non-critical scenario, especially if the user hasn’t experienced or revised the potential emergency situation for a period of time.

This phenomena has been demonstrated in a study by Geidl et al. (2011) where 18% of participants complained about misleading communication from the device, which then affected the resolution of a given problem. For example, the annoyance of the acoustic alarm, too much information on the emergency card, and fear of committing an operating error that might aggravate the problem.

Additionally, research conducted by the authors of this paper highlighted that throughout the training process and within emergency situations it is important to provide high fidelity visuals and critical information delivered in a streamlined, actionable manner. This could potentially improve patient and caregiver cognition by incepting a one-to-one conceptual map, or mental model. As expressed by a VAD caregiver during their interview:

“No animations, no diagram, do it real. Keep it really real. [...] When people are seeing it visually done, it makes sense."

 “[The way the doctors speak] It’s a different language that is spoken to me and that’s it. Talk in black and white. Not in colour. You’ve been at university for years learning in colour. We don’t need that. Just tell me black and white. Just tell me what I need to know.”

The importance of clear communication of information was also discussed by Geidl et al. (2011), uncovering that information structured as advice may be more easily understood than status information. For example, in the case of an unintended driveline disconnection, the advice of
“reconnect the blue cable with the blue connector” may lead to a faster reaction than “error: driveline disconnect” or other purely diagnostic information (Figure 6).

Figure 6 Simulating emergency response proficiency checks during VAD home life

6 Design Implications
In addition to the five design recommendations discussed above, one key design implication uncovered through the authors’ research was the insight that training should be focused on the caregiver during the rehabilitation stage, equipping them to feel confident and able. Additionally, important design considerations were uncovered for the design of a training tool for VAD patients and caregivers.

These included:
- Ensure patient confidentiality when dealing with data.
- Ensure the design of both digital and physical solutions meet accessibility guidelines.
- Ensure a frictionless experience in times of emergency.
- Ensure the language employed in the solution and documentation are respectful and understanding of the patient’s condition.

7 Further Research
It was a common theme throughout the authors’ research that the level of detail in the training provided by VAD physicians to patients and their caregivers was limited by the physician’s own training and understanding of the VAD lifestyle within a hospital context. A number of coping strategies (Jessie Casida, 2005; Savage & Canody, 1999) for daily life were innovated by VAD patients and caregivers themselves in an attempt to improve on their quality of life and minimise the struggles of activities they took for granted prior to treatment, such as showering.

The findings of this paper suggest that it is imperative to scale research in this area. Additional research could be conducted with a much larger multi-centre sample of current and past VAD patients and caregivers to uncover user-generated innovations, coping strategies and ‘life hacks’. These user-generated innovations could then be fed back into the training process in order to better prepare future VAD patients and caregivers with support tools, as well as inform practitioners and VAD manufacturers in order to potentially advance future clinical practice and VAD designs.
8 References


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Appendix A: Personas

Personas: VAD stakeholder personas included: a patient in the Introduction phase about to have a VAD implanted (top left); a patient in the Living phase who has lived with his device for two years (top right); a Caregiver in the Recovery phase beginning her VAD training (bottom left); and an extreme persona in the Adapting phase of a parent Caregiver having to care for their VAD child (bottom right).
### Appendix B: Journey Maps

<table>
<thead>
<tr>
<th>Phases</th>
<th>Introduction</th>
<th>Surgery</th>
<th>Recovery</th>
<th>Adapting</th>
<th>Living</th>
<th>End of Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient Actions</strong></td>
<td>Informing doctor of heart failure treatment options</td>
<td>Preparing for surgical/open heart surgery</td>
<td>Connected to ventilator &amp; medical equipment for a number of days</td>
<td>Making out of hospital</td>
<td>Accepting device on your lifestyle</td>
<td>BTT (donor possible, more surgery)</td>
</tr>
<tr>
<td></td>
<td>Research to understand LVAD</td>
<td>Life through training</td>
<td>Family support &amp; understanding</td>
<td>Accepting device</td>
<td>Adapted to limitations</td>
<td>DT (dealing with doctor)</td>
</tr>
<tr>
<td><strong>Patient Thoughts</strong></td>
<td>I’m overwhelmed by all of this, I need to make an informed decision</td>
<td>I think of the procedure</td>
<td>Will I ever get better?</td>
<td>My way of life has completely changed, I wish I knew how far it would go beforehand</td>
<td>I think I might be going wrong</td>
<td>The idea of more surgery is too much to bear</td>
</tr>
<tr>
<td><strong>Patient Goals</strong></td>
<td>To overcome their condition of heart failure</td>
<td>Have a successful procedure</td>
<td>To recover so they can return home</td>
<td>Learn to live with the LVAD</td>
<td>Become adjusted to a new way of living</td>
<td>Treatment is an overall success</td>
</tr>
<tr>
<td><strong>Touch Points</strong></td>
<td>Online resources</td>
<td>Paper resources</td>
<td>Doctor resources</td>
<td>Nurses</td>
<td>Hospital</td>
<td>Family</td>
</tr>
<tr>
<td><strong>Pain Points</strong></td>
<td>Fear of what the future might hold</td>
<td>Fear of complications</td>
<td>Sedentary and helpless</td>
<td>Learning about limitations (aerobic exercise, clothing, maintenance, feeding)</td>
<td>Fear of complications</td>
<td>Planning for the worst</td>
</tr>
<tr>
<td></td>
<td>Fear of complications</td>
<td>Physical appearance</td>
<td>Anxiety (device malfunction)</td>
<td>Awareness of borrowed time</td>
<td>Burden on family</td>
<td>Family support</td>
</tr>
<tr>
<td><strong>Opportunities</strong></td>
<td>Improve awareness of procedure</td>
<td>Improve awareness of potential complications to assist decision making</td>
<td>Provide easier access to rehabilitation services and support</td>
<td>Educate family member of ways to assist in the rehabilitation process</td>
<td>Develop products that help overcome anxiety and assist in the daily maintenance</td>
<td>Create a support network that assist with decision making</td>
</tr>
</tbody>
</table>