Building Relationships and Sustaining Dialogue Between Patients, Caregivers and Healthcare Practitioners: a design evaluation of digital platforms for ventricular assist device users

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Building Relationships and Sustaining Dialogue Between Patients, Caregivers and Healthcare Practitioners: a design evaluation of digital platforms for ventricular assist device users

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Technology-driven medical device design for the growing incidence of cardiovascular disease and heart failure has enabled ventricular assist device (VAD - a small mechanical pump which takes over the function of the heart) implantation as a treatment option. However, challenges are emerging with how patients’ and caregivers’ quality of life is negatively impacted during the VAD journey. Design innovation in digital platforms for VAD users can enable building relationships and sustaining dialogues between patients, caregivers and practitioners, which may improve outcomes. This paper details a content analysis methodology used to investigate sixteen digital platforms designed for VAD patients, caregivers and practitioners. Most digital platforms supported the primary purpose of daily home monitoring or stakeholder education, and featured varying levels of interactivity, communication and focus through the different stages of the patient journey. This paper suggests five implications for future digital platforms designed to support VAD users: embrace the entire patient journey, emphasise human-centred design over patient-centric design, encompass holistic wellbeing, enable communication channels, and blend ‘manual input’ with ‘smart input’ interactivity.

patient centric design; human centred design; user experience design; design innovation
1 Introduction
Significant advances in support for patients suffering advanced heart failure have been made since the first successful clinical use of cardiopulmonary bypass in 1953 when mechanical circulatory support (MCS) became a reality (Schumer, Black, Monreal, & Slaughter, 2016). From early beginnings in the 1960s, followed by a collaboration between scientists, device engineers and the heart transplant community, the Novacor Left Ventricular Assist Device (LVAD) was implanted as a bridge to heart transplantation in 1984 (Kirklin & Naftel, 2008). This led to a surge in regulatory approval for VADs throughout the 1990s (Schumer et al., 2016). Since then, Ventricular Assist Devices (VADs) have been miniaturised and further improved to demonstrate better durability and a reduction in noise levels, but more importantly, a reduction in complications and increased patient survival rates (Kaan, Young, Cockell, & Mackay, 2010a; Kirklin et al., 2017; ReliantHeart, 2017; Rose et al., 2001; Schumer et al., 2016).

In the United States, approximately 5.7 million adults were afflicted with heart failure in 2015, with this figure projected to increase to 8 million by 2030 (Go et al., 2013; Heidenreich et al., 2013; Mozaffarian et al., 2016). Meanwhile, in Australia, over 167,000 hospitalisations saw heart failure and cardiomyopathy recorded as either the principal or secondary diagnosis, representing 1.6% of all hospital admissions during 2014–15 (Australian Institute of Health and Welfare, 2016). The number of patients awaiting heart transplantation has doubled within the last 15 years (Prinzing et al., 2016) yet only a steady rate of global heart transplant activity with very little increase has been observed from 2011-2015 (The World Health Organization (WHO) & Organización Nacional de Trasplantes (ONT), 2015). It is obvious that the quantity of donor organs available is insufficient to support patients who are awaiting heart transplantation.

A Ventricular Assist Device (VAD) is a mechanical pump that takes over the pumping function of a single ventricle as an alternative to immediate heart transplantation, which isn’t always available. VADs can support end stage heart failure patients while they are waiting for a future donor organ transplant (Brigitta Bunzel, Laederach-Hofmann, Wieselthaler, Roethy, & Wolner, 2007; Jakovljevic et al., 2014). The development of VADs has led to overall improved quality of life for patients diagnosed with heart failure and afforded increased survival time, since over 40% of patients worldwide waiting for heart transplantation have been implanted with a VAD (Schumer et al., 2016). Thus, VADs have become an important and widely accepted treatment option for severe, acute, and chronic heart failure with four key use scenarios: (1) bridge to transplantation, (2) bridge to decision, (3) bridge to recovery, or (4) as destination therapy (i.e., as a substitute for transplantation for patients who not suitable for transplantation) (Boling, Hart, Okoli, & Halcomb, 2015; Jakovljevic et al., 2017; Kaan et al., 2010a; Makdisi, Makdisi, & Bittner, 2017; McLarty, 2015; Prinzing et al., 2016; van Manen, 2017).

However, current VAD solutions, including the device itself, support tools, and systems surrounding VAD implantation still require more thoughtful designs to optimise the patient experience. A greater understanding of the impact of inserting a complex mechanical device into an even more complex and nuanced human experience should be considered as prerequisite, and is within the domain of design expertise. Moreover, all stakeholders including patient, caregiver (e.g., a spouse, family member, or a friend who can provide fulltime help and support), cardiologist, surgeon and nurses and their main touch points of interaction with the device must be considered throughout the design development process. Patient support tools should facilitate building relationships and sustaining dialogues between stakeholders in order to improve the overall VAD implantation experience for all users, and improve patient outcomes. This challenge becomes even more critical when we consider the rising number of VADs implanted in patients and the global increase in heart disease (Go et al., 2013; Heidenreich et al., 2013; Koprivanac, Kelava, Cruz, & Moazami, 2014; Mozaffarian et al., 2016).
If we draw our focus towards VAD support tools, currently there are several digital platforms available for this very purpose, each with different aims, content, focus, and audience. There is evidence to support the emergence of digital platforms for VAD users in recent years (Casida, 2017; Hawkins, Ventresco, & VanderPluym, 2017; Husain, 2016; K. Kostick et al., 2016). This paper therefore explores the key challenges associated with digital platforms designed for VAD users, and outlines a range of design implications and recommendations for how designers of such platforms could either improve future designs, or design new digital platforms that better fulfil patient, caregiver and practitioner needs.

The paper is structured as follows. First, a literature review is presented, outlining the current state of the VAD field, and a summary of the fundamental needs of each major user group – i.e. patients, caregivers and health practitioners. Following this, the authors examine specific design approaches which may assist in the creation of a more positive user experience for VAD patients, and for better enabling and empowering caregivers and health practitioners to support patients at each stage of the VAD journey. By improving the experience for all VAD users (i.e., VAD patients, their caregivers, and their health practitioners), the authors anticipate a flow-on benefit for the overall wellbeing and quality of life of VAD patients. A content analysis of existing digital platforms for VAD users is therefore presented to outline the state of this emerging field, to decipher which stakeholder requirements were being met, and to identify and consolidate unmet needs into a set of design recommendations. Finally, this paper presents the gaps and opportunities for the design of digital platforms for VAD patients, caregivers and practitioners, the limitations of the current study, and opportunities for future research.

2 Building Relationships for a Better Quality of Life

The importance of quality of life and assessment of the patient’s experience is broadly acknowledged in health care and healthcare research, although some confusion remains about how to measure this (Muldoon, Barger, Flory, & Manuck, 1998; Schumer et al., 2016). A heart failure patient’s physical condition generally improves after VAD implantation (Starling, 2010) however the associated negative impact on both the patient and their caregiver’s quality of life is still questionable, especially from the perspective of the longer-term emotional consequences (B. Bunzel, Laederach-Hofmann, Wieselthaler, Roethy, & Drees, 2005; Brigitta Bunzel et al., 2007; Jessie Casida, 2005; Kaan et al., 2010a). In order for VAD implantation to become a better therapy option for patients with heart failure, an improvement to both a patient’s physical and psychological long-term quality of life should be considered as a prerequisite.

Muldoon et al. advocated that patient quality of life can be identified by two operational definitions, ‘objective functioning’ which relates to an individual’s physical status, and ‘subjective wellbeing’ which relates to an individual’s psychological status (Muldoon et al., 1998). It is suggested that the subjective evaluation of wellbeing could be influenced substantially by psychological factors which might not be directly related to health; or could change over time as a patient’s criteria and perception of wellbeing changes. We know there is a correspondence between physical wellbeing and health, and as the prevalence of chronic illness increases with advancing age this may become more significant as people grow older, (Steptoe, Deaton, & Stone, 2015). However, psychological wellbeing is affected by many factors other than physical health. These include material conditions, social and family relationships, and social roles and activities. The design of a digital platform for VAD users can thus (1) assist with motivating patients and their caregivers to perform beneficial behaviours and activities that improve material conditions, and (2) encourage social connection by building relationships and sustaining dialogues between patient and caregiver, patient groups, caregiver groups, patient and practitioner, caregiver and practitioner, and even between practitioners.
2.1 A Patient Perspective

Living with a VAD requires extensive commitment to its daily monitoring and maintenance, and has a considerable effect on a patient’s body and sense of self (Chapman, Parameshwar, Jenkins, Large, & Tsui, 2007). Factors influencing the quality of life of VAD patients are diverse and could include levels of pain, apprehension, depressed mood, and functional impairment (Muldoon et al., 1998). Patients experience emotional shock and both physical and emotional scarring, and key themes emerge around confidence and trust in the machine keeping them alive and in their own bodies’ capabilities (Chapman et al., 2007). In addition to their overarching condition of heart failure all VAD patients have a risk of suffering from blood clotting, stroke, bleeding, infection, organ malfunction, device failure, and right heart failure (Schumer et al., 2016; Starling, 2010), with a likelihood of increasing the level of a patient’s emotional distress. Being restricted by their physical activities, unable to drive, swim or take a bath (Starling, 2010), and unable to travel any significant distance (especially on a plane) contributes to patients feeling isolated and depressed. Moreover, VAD patients can experience body image disruption because unlike, for example, a fully implanted pacemaker, a VAD is technically only partially implanted because it has both an internal device and external percutaneous drive lines, controller unit and power supply (Chapman et al., 2007; Starling, 2010). In addition to these components, some VAD patients are expected to experience symptoms of post-traumatic stress disorder (PTSD), especially after heart transplantation (B. Bunzel et al., 2005).

2.2 A Caregiver Perspective

In most cases, VAD patients require one or more dedicated caregivers at home since the complex management required of the VAD lifestyle does not support independent living. Caregivers are likely to experience fear and anxiety, and are often overwhelmed by the initial stages of the journey (Casida, 2005), which can escalate quickly depending on the urgency of the VAD implantation. They describe their role as difficult, and continue to feel losses of various kinds throughout the VAD experience, such as the need to stop work or live away from their own communities (Kaan et al., 2010a). It is clear that taking on a fulltime role of VAD caregiver and the associated commitments increases a caregiver’s stress levels significantly (Kaan et al., 2010a).

Research has revealed that more caregivers are experiencing PTSD than the VAD recipients’ themselves (B. Bunzel et al., 2005; Brigitta Bunzel et al., 2007; Kaan et al., 2010a), with the majority of caregivers being female (e.g., a partner or spouse of male patients). Female caregivers are even more likely to experience adverse psychological distress than their male partners, since women are more vulnerable than men to experience PTSD symptoms after exposure to trauma (B. Bunzel et al., 2005). This highlights the need to “support the support person” (B. Bunzel et al., 2005), since there are significant levels of emotional burden and risk of developing anxiety disorders for VAD caregivers over the longer term.

2.3 A Healthcare Practitioner Perspective

Current designed digital platforms for VAD users are applicable for healthcare practitioners in three ways. First, digital platforms can be information enhanced for point of care, thus healthcare practitioners can either use these to update their own knowledge or convey that knowledge to patients and their caregivers. Secondly, digital platforms can function as a Decision Support Tool (DST) that can assist healthcare practitioners to make a well-informed decision whether or not to implant a VAD (Yang, Zimmerman, Steinfeld, Carey, & Antaki, 2016). For a DST to be truly useful to, and adopted by, a practitioner it must carefully take into consideration clinical reality and understand the practitioner’s work practices, workflow integration, the context where decisions are made, and other critical factors that can influence a medical decision (Yang et al., 2016). The third use of a digital platform from the perspective of a VAD practitioner is to enable the remote monitoring of patients. This allows patient data to be automatically conveyed to their practitioner and digital records to be formed, accessed and maintained, and can potentially streamline the practitioners’ workflow and reduce administrative elements. Additionally, giving practitioners a secure platform to establish and sustain a dialogue, and build a relationship with their patients and
Caregivers may mean that adverse issues, anomalies, and difficulties can be detected by the practitioner early, giving them greater control and influence over patient outcomes.

3 Usability, User Experience Design and Human-Centred Design

An understanding of the holistic user experience is important in the design of medical devices, as optimum usability is created when both physical and psychological human capability and limitations are designed into the patient experience. Evans & Geiselhart (2012) identified a set of usability factors that should be considered when designing medical devices and their associated systems, these include:

- **Physical abilities**, including anthropometry, biomechanics and sensory abilities.
- **Cognitive abilities**, including how the brain processes information, the capabilities of memory, the manner in which humans learn new things, and how habits are developed.
- **State of being**, including the general health of expected users, disease states and comorbidities likely to challenge patients’ mental and emotional states, and motivation for learning new things.
- **Experiences**, including educational backgrounds, knowledge of particular disease states, and lifelong experiences with objects that will guide behavioural interactions with any delivery system.

The ultimate success of a product or service is determined when the users are first willing to use, and secondly find the product or service they have been offered to be useful (Martin, Clark, Morgan, Crowe, & Murphy, 2011). Likewise, the experience can be measured by how well users understand the product and service, the users feeling towards the product or service during usage, how well the user receives the purpose of it, and how well it fits into the context of the user (Bate & Robert, 2007). Introducing the user experience early in the design process could considerably reduce development time because usability problems are able to be identified and resolved before the systems are launched. Additionally, when the focus is kept upon meeting the users’ needs with a more accurate understanding of both user requirements and barriers for adoption and regular use, a higher level of user acceptance can be achieved (Martin et al., 2011).

User experience design implies that designers shouldn’t be limited to designing only for patients as is the case with patient-centric design, but should also incorporate the needs of other major stakeholders (including caregivers and healthcare practitioners in this context). Caregivers and healthcare practitioners have the greatest degree of responsibility to look after patients, are accountable for most health-related tasks, are on the front line of managing patient health risks, and are actively supporting patients in various circumstances throughout the entire patient journey and beyond. Therefore an emphasis should be placed on incorporating a human-centred design approach as opposed to a patient-centric design approach, wherein human-centred design brings the experience of all users to the core of the design process and through the use of “techniques which communicate, interact, empathize and stimulate the people involved,” obtains “an understanding of their needs, desires and experiences which often transcends that which the people themselves actually realized” (Giacomin, 2014, p. 610). A human-centred design approach will thus increase the likelihood of designing a product or service that meets the users’ needs (Kouprie & Visser, 2009; Krippendorff, 2004).

4 Medical Device Design and Innovation

Medical device manufacturers create life-changing innovations through the collaborative expertise of various disciplines including engineering, manufacturing, clinical, regulatory, marketing, sales and business specialists, with the role of the designer often being that of user advocate, providing insight and opinion (Privitera, Southee, & Evans, 2015) as well as aesthetic design, form giving, human factors application and testing, along with implementing contextual inquiry/ethnography methods.
Appropriate use of design ensures that the optimum user experience is championed from early on in the process and throughout the development process as design trade-offs need to be made (Norman, 1986).

While cutting-edge technology advancement in medical device design is indisputably valuable, patients and caregivers don’t necessarily notice the sophisticated underlying technology behind a medical intervention – they notice the entire experience from cognitive and emotional level (Bate & Robert, 2006) as they interact with the whole medical device system. Exemplary medical device design should integrate technology development with user needs (Martin & Barnett, 2012). That is, human-centred design should function an enabler of technological innovation, because “the involvement of users in medical device technology development and assessment is central to meet their needs” (Shah & Robinson, 2006, p. 500). However, much advancement in medical device design is firstly driven by technological advances, with the fulfilment of patient or practitioner needs as a secondary result of the technology discovery. As Martin et al. (2008, p. 275) state, “currently, users are generally not brought into the developmental process until after the design brief for a new product has been produced. This may be because medical devices are frequently technology driven rather than resulting from an identified unmet need” (Martin et al., 2011, 2008). However, design innovation does not occur solely through technology development and feasibility as can be seen in Figure 1, it occurs through the intersection of technology with desirability of a solution that fulfils of user needs, along with viability of the business model (Brown, 2009).

One type of tool that (1) doesn’t rely on further cutting-edge technology discovery for present-day implementation and (2) can help improve the overall patient experience through task management, education, or by providing appropriate communication channels, is what the authors have called a ‘designed digital platform’. In this paper, a designed digital platform has been defined as an application, website or portal created specifically for VAD users, that is, patients, caregivers or practitioners.

This paper focuses specifically on the digital platforms that support VAD patients, practitioners and carers because the big picture industry challenges that are emerging with a growing incidence of heart disease, heart failure and VAD implantation (Go et al., 2013; Heidenreich et al., 2013; Koprivanac et al., 2014; Mozaffarian et al., 2016) can be met with patient-centric designs that don’t have to be technology-driven, but can be created with attention to the user experience (Martin et al., 2011). We can see a trend materialising as designed digital platforms for VAD users are emerging along with the VAD industry as a whole, due to an increasing recognition of the need for tools to

Figure 1 Design Thinking framework by Tim Brown (Brown, 2009)
assist with the decision-making process, practitioner education, patient and caregiver education, daily maintenance and monitoring, self-care, and wellbeing management (J. M. Casida, Aikens, Craddock, Aldrich, & Pagani, 2017; Jesus Casida, 2017; Hawkins, Fynn-Thompson, et al., 2017; Hawkins, Ventresco, et al., 2017).

There appears to be a new segment of digital platforms for VAD users being researched, developed and launched within the past 3-4 years. A content analysis of digital platforms for VAD patients, caregivers and practitioners was therefore undertaken in order to (1) better understand the current state of the field, and (2) to generate theories about the design of digital platforms for VAD users. From this increased understanding, the intention is to investigate design implications and possibilities for future digital platforms for VAD users, and develop a new digital platform that could be used to improve the entire VAD patient journey. This research is novel as previous innovation in this context has been largely focused on technical innovation.

It is not simply VAD manufacturers who may wish to better address the patient journey of their users, but in fact many third-party groups are showing interest in the digital patient engagement space with multidisciplinary teams being assembled from different facets of medical, clinical, business and technology fields working together to address new and evolving needs. This presents an opportunity for designers and design innovators who may be brought onto such multi-disciplinary development teams to become involved in the development of new solutions – ideally at the earlier stages rather than later.

5 Method
A content analysis methodology (Elo & Kyngäs, 2008) and investigator triangulation (Begley, 1996) techniques were used to chart what digital channels are currently being used by VAD patients, caregivers and practitioners. The authors used Straker et al.’s (2015, p. 113) definition of a digital channel as technology-based platforms that use the internet to:

- Connect with customers via digital technology;
- Provide a range of different content and purposes; and
- Facilitate communication with a range of different interaction levels.

For the purposes of this research, the authors have limited the scope of digital channel analysis to ‘designed digital platforms’, defined as digital technology-based applications, websites or portals that have been created specifically for the use of VAD patients, caregivers and practitioners. Selection of the digital platforms was not restricted by the party behind each platform’s creation, allowing for the inclusion of third-party platforms. The authors explicitly excluded touchpoints such as social media networks, private blogs and informal online communities (e.g. Facebook groups) in the content analysis, as these platforms have not been designed specifically for VAD patients, caregivers or practitioners as their core customer, and cannot offer services such as secure exchange of sensitive patient data, or private communication between the patient/caregiver and health practitioner. Additionally, the way that social media is used as a virtual community and support group by VAD patients has been explored previously by Boling, Hart, Okoli, & Halcomb (2015) and the scope, content and quality of social media related to left VAD has been examined in a detailed content analysis and principle components analysis by Kostick, Blumenthal-Barby, Wilhelms, Delgado, & Bruce (2015). While the existence of designed digital platforms for VAD users has been on the increase over the last 5 years, and several individual case studies of designed digital platforms (such as patient-centred apps) for VAD users could be found in the academic literature, so far there has not been a comparative content analysis of such platforms.

Each designed digital platform in the study was therefore purposively sampled (Guest, Bunce, & Johnson, 1995; Sandelowski, 1995) based on the inclusion criteria of being:

- A designed digital platform (application, website or portal);
• Created specifically for patients, caregivers or practitioners; and
• Under development, under clinical trial, or in use by VAD users.

Data was collected from a variety of publicly available online sources. To negate any potential bias in the findings, the authors used an investigator triangulation (Begley, 1996), whereby each researcher analysed the data independently. Each researcher then compared results, and an appropriate level of common agreement was found.

Analysis took place over three phases. The first phase involved discovering the development and use of digital platforms by VAD patients, caregivers, hospitals and medical practitioners. This was achieved through the use of publicly available sources to detect the presence of digital platforms for VAD users, and filter any digital platforms that were not designed specifically for those involved in the VAD patient journey. Any website or app, particularly those designed for heart failure or generic medical device self-management that had no reference to VAD implantation was excluded from the research. Some of the search terms used included “Ventricular Assist Device app”, “VAD app” and “LVAD app”. Both scholarly material as well as a variety of online sources were surveyed. During the first phase, these designed digital platforms were classified according to whether they were ‘Patient / Caregiver centric’, ‘Practitioner Centric’ or both ‘Patient / Caregiver and Practitioner centric’. For the purposes of this research and simplicity of classification, patients and caregivers were grouped together as users as they form a care partnership in the VAD journey, and ‘Practitioners’ is an umbrella term the authors have used to refer generally to healthcare professionals including but not limited to nurses, intensivists, social workers, psychologists, surgeons and cardiologists.

The second phase involved tabulating the results of phase one and determining the name of the platform, the company, founder or sponsor, when the platform was last updated, the location, the development phase or project status, the primary user or audience, the technology or device platform (e.g. website, iOS or Android), the main purpose, interactivity, communication, focus, and whether the designed digital platform was available to the research team. Finally, phase three involved using a thematic analysis approach (Braun,V & Clarke, 2006) to identify patterns in the data.

6 Findings

The authors were able to make a range of observations from the sixteen designed digital platforms chosen for assessment, listed in Table 1, and were able to identify patterns in the data, (detailed in Appendix. Table 3 and Table 4). Of the digital platforms for VAD users presented in this paper, most were currently in use and updated within the previous two years, with two platforms nearing obsoletion, and some of the more interesting digital platforms for VAD users were still in the developmental or trial phase. Cross-platform digital solutions (i.e., those that could be used on a range of platforms such as iOS, Android, phone, tablet, desktop computer, kiosk, and web-browser, and not just isolated to any one digital channel or device) were more prevalent, and by default these allow more universal access by various users.

Only eleven out of a total sixteen platforms were available for the researchers to assess as some platforms were region specific and not accessible from Australia, or were still in development or only for use with a purchased device. Moreover, the authors found that most of the digital platforms for VAD users were developed for the US market, with the exception of one Japanese platform. So far, no solution existed specifically for the authors’ Australian context.

The most common primary purpose of digital platforms for all users was for daily at-home patient monitoring, followed by educational. Most practitioner-centric platforms were educational and offered either one-way communication or limited communication ability between the practitioner and the digital platform.
Table 1  Comparison of designed digital platforms for Ventricular Assist Device users

| No. | Name                      | User / Audience                  | Platform                           | Purpose                                           | Interactivity | Communication | Focus              |
|-----|---------------------------|----------------------------------|------------------------------------|--------------------------------------------------|---------------|---------------|--------------------|
| 1   | CORA Patient Counsellor   | Patients & caregiver and Practitioner | Website                           | DST (Decision Support Tool) and educational      | Manual input  | Two way        | Multiple stages    |
| 2   | Deciding Together         | Practitioner                      | Website, downloadable PDF          | DST (Decision Support Tool)                      | No Input      | In between     | Specific stage     |
| 3   | Harvi                     | Practitioner                      | iPad app, website                 | Educational                                       | No Input      | One way        | Specific stage     |
| 4   | Heart Failure Health Stories | Patients & caregiver             | Mobile & web app; Android and iOS  | Daily home monitoring                            | Manual input  | In between     | Multiple stages    |
| 5   | Heartmate 3™              | Practitioner                      | Android and iOS app                | Educational                                       | Manual input  | One way        | Specific stage     |
| 6   | John Hopkins ABX Guide    | Practitioner                      | Website, app for iOS and Android devices | Educational                                       | No Input      | One way        | Specific stage     |
| 7   | LVAD Calc                 | Practitioner                      | iOS app                           | DST (Decision Support Tool)                      | Manual input  | One way        | Specific stage     |
| 8   | LVAD@home and LVAD@care  | Patients & caregiver and Practitioner | iPad app                      | Daily home monitoring                            | Manual input  | Two way        | Multiple stages    |
| 9   | MyLVAD                    | Patients & caregiver              | Website (plus MyLVAD hospital locator app for iOS and Android) | Community support and educational                  | Manual input  | Two way        | Entire journey     |
| 10  | Qualia Health - Health Check Qualia Plus - Health Score and Tracker | Patients & caregiver             | iOS App                           | Daily home monitoring                            | Manual input  | Two way        | Entire journey     |
| 11  | ReliantHeart HeartAssistRemote ™ Monitoring | Patients & caregiver and Practitioner | Website, app, hospital console | Daily home monitoring                            | Smart input   | In between     | Multiple stages    |
| 12  | VAD Care App              | Patients & caregiver and Practitioner | App - unspecified                | Educational and daily home monitoring            | Manual input  | Two way        | Multiple stages    |
| 13  | VADKids®                  | Patients & caregiver and Practitioner | iOS app                          | Daily home monitoring                            | Manual input  | Two way        | Multiple stages    |
| 14  | VADWatch® and Alere™ VADCare® Program | Patients & caregiver and Practitioner | Smartphone, tablet or computer | Educational and daily home monitoring            | Manual input  | Two way        | Entire journey     |
| 15  | Vidscript                 | Patients & caregiver and Practitioner | Website, iOS and Android app     | Educational                                       | Manual input  | In between     | Multiple stages    |

Communication has been defined along a spectrum, whereby:

- ‘One-way’ implies passive consumption of information by a user (for example reading, watching, or listening),
- ‘In between’ refers to a basic ability to communicate by filling out a question and answer form or worksheet for discussion, tick boxes, or simple data entry to get an automatically generated answer) and
- ‘Two-way’ describes the ability to communicate between more than one human party using the platform (for example, questions, queries and images are sent to an actual practitioner to get feedback, or the platform hosts an interactive patient forum).
Similarly, each of the sixteen designed digital platforms for VAD users in Table 1 was assessed for level of interactivity. The authors have defined the interactivity spectrum as follows:

- **No input** – No information needs to be input into the digital platform itself to gain information output (for example, downloadable / accessible information such as a PDF or video).
- **Manual input** – Patients, caregivers or practitioners enter in data manually to experience the full suite of resources the digital platform offers. This is a step up from pen and paper worksheets that allows data to be instantly collected and trends to be seen over time, but still may require many steps and consistent effort to input.
- **Smart input** – Data is input to the digital platform automatically via connected devices (e.g. VAD or other communication-enabled patient monitoring device) in order to reduce the number or tasks and potential for human error (for example, a blood glucose level monitoring device automatically refers result to digital platform, or a digitally connected VAD with remote monitoring capability).

Most of the digital platforms required some kind of manual data input for interactivity, and only one platform offered some level of smart integration with existing consumer fitness trackers. Likewise, just one smart connected VAD-system solution existed (ReliantHeart, 2017), and was only available and approved for use in Europe at the time of analysis (though under clinical trial in the US).

A substantial number of the digital platforms had been designed with both the patient/caregiver pair and practitioners in mind, but when we looked more closely among these, each platform was skewed towards either being practitioner-centric or patient-centric. Furthermore, patient-practitioner platforms that enabled two-way communication were not inherently social (patient-to-patient) whereas the only platform that was classified as being both patient-centric and also enabling a high level of two-way communication, MyLVAD, was also distinctly social (patient-to-patient). However, it was noted that this platform was not actively moderated by practitioners which may lead to misleading information being shared (K. M. Kostick et al., 2015) and patient questions going unanswered.

Most platforms that functioned as DST did cover the pre-implantation stage but were noticeably practitioner-centric. The exception to this was the CORA Patient Counsellor platform which attempted to target both patients/caregivers and practitioners in its design, but the platform’s communication-style was still distinctly practitioner-toned. The authors observed how this platform offered a wealth of educational tools but could appear insensitive to patient emotions, that is, the tool demonstrated a lack of empathy toward the patient experience, with abrupt statistical communication about potentially sensitive topics such as predicted patient survival rates and mortality.

A considerable majority of the digital platforms designed for VAD users covered multiple stages of the patient journey, with only two offering support to the entire journey. Interestingly, the bulk of patient-focused training about the hands-on daily tasks required for living with a VAD appeared to be delivered at a point on the journey soon after implantation, with the exception of the VADKids® platform and its associated program, which aims to train parents using simulations in order to increase confidence of care before implantation and bringing the VAD patient home (Hawkins, Fynn-Thompson, et al., 2017; Hawkins, Ventresco, et al., 2017; Transplant Talk, 2017; Vector blog, 2017). The designers of the VADKids® platform recognised a greater need for practical, scenario and task-based caregiver and patient training prior to discharge from hospital.

## 7 Discussion

One key area where a distinctive gap in the competitor landscape could be identified was in the level of interactivity of digital platforms for VAD users. The research supports that each of the three interactivity typologies ('no input', 'manual input' and 'smart input') performs a different function. A
level of interactivity on the ‘no input’ end of the spectrum is useful where the information supplied would be common to all VAD users and there is no need for a personalised variation of the information supplied. All three platforms assessed which required no user input for the platform to function were practitioner-centric, and offered simple delivery of educational material for a practitioner to refer to via a digital textbook, as a reference guide at point of care, or PDF worksheets to fill out offline. The problem with this low level of interactivity is that these platforms do not take advantage of the gamut of benefits that are afforded by more sophisticated digital platforms with a higher level of interactivity. The main benefit is simply being able to carry a large amount of information in one’s pocket to access when needed.

A level of interactivity that requires ‘manual input’ is the logical next step forward for VAD user digital platforms because VAD patients and their caregivers must collect large amounts of daily data to submit to practitioners for monitoring and review. The authors found that the majority of designed digital platforms for VAD users came under this category and for this reason, the category is by no means homogenous. Each of the platforms that fell under this category exhibited a wide range of interactivity inputs, from one-off data inputs needed to calculate patient risk, all the way up to input that allowed practitioner-to-patient or patient-to-patient communication channels. Digital platforms that enable self-care are still useful for helping patients to adapt the ‘new normal’ of life with a VAD, for example by sending push notifications that remind patients and their caregivers to collect clinical information and pump parameters to submit to practitioners from home after surgery (J. M. Casida et al., 2017). The limitation of manual input with no level of smart input is that the quality of the data is subject to human error and input consistency.

Finally, on the other end of the interactivity spectrum, we have ‘smart input’. While ‘smart input’ is not a blanket replacement for all manual input, since it is only useful for objective data, we could still expect that many day-to-day tasks requiring manual input of data by VAD patients and their caregivers could be replaced by connected devices with sensors that automatically detect and then input patient data to a digital platform. In this way, the practitioner could access the objective data that they need without the barrier of the patient or caregiver having to act as a conduit for that information. That is, the process of data flow would be seamlessly sent straight from the VAD (or associated) device, via a digital platform, to the patient’s practitioner, without the patient or caregiver intermediary, as in the case of ‘manual input’. However, subjective data (e.g., a personal wellbeing assessment, or symptom journal) would still require manual input.

This research suggests that a major benefit of automatic ‘smart input’ is the ability to reduce task burden, mental load and stress on patients and caregivers, so that they may focus their energy on tasks that cannot be automated, for example, regular exit site cleaning and dressing (Jessie Casida, 2005). Currently, the authors could find only two examples of platforms which demonstrate a level of ‘smart input’ interactivity – i.e., platforms that were designed to enable communication between a physical device (one being an off-the-shelf consumer fitness tracker and the other, an implanted VAD flow sensor) and the designed digital platform. Device-to-digital-platform smart input is only one part of the story, however. The next level is (1) integrating the automatic data input with (2) additional complimentary data input manually by the patient/caregiver then (3) consolidating this on the one platform, and then (4) allowing the patient’s practitioner secure access to this data for remote monitoring.

8 Design Implications and Recommendations
We draw the following five implications from our findings to inform and inspire digital platform designers in exploring new design possibilities and creating future solutions to support VAD users (Table 2): (1) embrace the entire journey, (2) emphasise human-centred design not patient-centric design, (3) encompass holistic wellbeing, (4) enable communication channels, and (5) blend manual input with smart input.
8.1 *Embrace the entire journey*: Digital platforms for VAD users should support a wider part of the patient journey – from heart failure diagnosis, decision support, pre-implantation training using simulation, post-implantation life, then finally to explantation. This could potentially lead to better patient outcomes as the journey is supported from beginning to end as opposed to individual situation-specific tools that do not work together and could lead to a disjointed, confusing experience. The patient journey would best be considered from a system design perspective, whereby each touch point is considered to make up a constellation of the whole experience (Bate & Robert, 2006). The heart failure journey starts long before a decision to implant a VAD is even made. While VAD manufacturers are limited to serving a highly specific therapeutic purpose at one point in the patient journey, a better overall experience may be designed by considering the wider patient journey and the processes leading up to decision, all the way through to potential recovery. However, this calls for functional integration.

8.2 *Emphasise human-centred design, not patient-centric design* Patient-caregiver pairs are not the only stakeholders in the VAD journey, and do not exist in a vacuum. As such, it is not enough to design a patient-centric platform exclusively for patients and their caregivers without also considering their healthcare practitioners and the wider system. In the content analysis presented in this paper, we noticed that for a digital platform design to be truly considerate of the nuanced and complex needs of patients and caregivers, it must also consider the needs of the practitioner. It is more appropriate, then, that the design of future digital platforms for VAD users embodies the philosophy of human-centred design and not just patient-centric design, which may exclude the wider design context and miss opportunity areas.

Table 2  Summary of design implications of digital platforms for VAD users during the entire patient journey

| JOURNEY | PRE - DURING including 6 weeks post-surgery | POST - Human centred | EMPHASIS | Communication Channels | Interactivity | Wellbeing |
| --- | --- | --- | --- | --- | --- | --- |
| PATIENT - Education, Decision making tool | Training, Start monitoring | Daily home monitoring and communicating with practitioners | Understand physical and psychological limitation | Practitioner moderation, future platforms for patient-to-practitioner, patient-to-patient social networking | Blend manual input with smart input for remote monitoring purposes and communication | Factors including mental, emotional and social health with physical factor |
| CAREGIVER - Help training patients and caregivers | Training, Start monitoring | Understanding fear, anxiety, overwhelm, stress and commitment | | | |
| PRACTITIONER - Help training patients and caregivers | Receiving information and analysing | Understand the workflow and clinical reality | | | |

8.3 *Encompass holistic wellbeing* Future designed digital platforms for VAD users should consider not only physical health and clinical parameters but holistically integrate overarching wellbeing factors. The authors of this paper acknowledge the significance of addressing the spectrum of wellbeing factors including mental, emotional and social health with physical factors as a part of holistic self-care management in VAD patients and caregivers who can experience a range of challenges from physical concerns, to
psychosocial issues and the need to form adaptive behaviours to cope with the ‘new normal’ of daily life with a VAD (Jessie Casida, 2005; Chapman et al., 2007; Kaan, Young, Cockell, & Mackay, 2010b; Pérez-García, Oliván, & Bover, 2014; Savage & Canody, 1999).

8.4 Enable communication channels
Digital platforms for VAD users should continue to provide patient-practitioner communication channels, and patient-to-patient channels. Ideally, future digital platforms could be designed to facilitate both communication needs, as opposed to focussing on just one or the other. That is, future platforms that are designed as patient-to-patient channels should include some kind of practitioner moderation, and future platforms that are designed for patient-to-practitioner could also facilitate patient-to-patient social networking.

8.5 Blend manual input with smart input
Future VAD platforms need to become more than just digital substitutes for the pen-and-paper forms and worksheets currently used by patients and caregivers. An increase in interactivity level of the digital platform towards the ‘smart input’ end of the spectrum is one key area where progress can be made. Future digital platforms for VAD users should attempt to reduce patient, caregiver and practitioner task burden and mental load by having smart input for objective data, while maintaining the ability to manually input subjective data for remote monitoring purposes and communication with the healthcare practitioner.

Figure 2 Design Innovation for patients, caregivers and practitioners in VAD digital platforms, building on Design Thinking framework by Tim Brown (Brown, 2009)

9 Future Work
As this study was based on content analysis of secondary data, an important direction for future research would be to conduct detailed analysis with primary data, working directly with patients, caregivers, hospitals, and practitioners including nurses, intensivists, surgeons and cardiologists. Additionally, it has been stated that “a general limitation of content analysis is that it is a descriptive method, i.e. it is able to characterise existing, documented phenomenon”, and “it is unable to reveal the underlying design rationales or motives for the observed patterns” (Straker et al., 2015). Therefore, further research is needed to uncover these design rationales and assess the effectiveness of the current digital platform designs for VAD users. Additionally, the research team
intend to design, develop and test a new designed digital platform for VAD patients, caregivers and practitioners in Australia, based upon the design implications and recommendations discussed above.

Future work could involve creating and producing a new designed digital platform (such as an app, website and/or portal) for VAD users based upon patient, caregiver and practitioner feedback, refining and detailing the design, then bringing this refined prototype to a representative sample of patient/caregiver pairs to assess the effectiveness and ease of use of the design proposal. From there, clinical studies and implementation could test the success of the digital platform intervention in improving quality of life measurements against quality of life without using a digital platform.

In addition, future research could explore how digitally-connected smart devices and automated data input could significantly impact the patient and caregiver experience by reducing the task burden and mental load of daily VAD management, while improving practitioner workflow. Yet future research could explore if monitoring adverse events actually reduces their occurrence. It is not too optimistic to envisage a future of digitally connected VAD and home health monitoring device systems that, when paired with the appropriate sensors, communications units, machine learning and intelligent back-end algorithms, could be used to detect health setbacks or events of deteriorating patient condition as they occur, and therefore improve positive patient outcomes.

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| No. | Name                          | Description                                                                                   | Company / Founder / Sponsor                                                                 | Last Updated | Location       | Development Phase / Status | User / Audience | Platform   | Purpose                  | Interactivity | Communication | Focus | Currently accessible to our research team? |
|-----|-------------------------------|-----------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------|--------------|----------------|-----------------------------|----------------|------------|---------------------------|--------------|---------------|-------|-----------------------------------------|
| 1   | CORA Patient Counsellor       | A service designed for both patients and physicians to assist in the decision for VAD therapy, as well as provide supplementary resources for post surgery care. It offers interactive tools as well as a variety of informative videos explaining the VAD, the surgery, and testimonials from patients. | Carnegie Mellon University - Allegheny Health Network Pittsburgh, PA, USA, and Presbyterian... | 2015         | Pittsburgh, PA, USA | In use                      | Patients & caregivers & Practitioner | Website     | VAD (Decision Support Tool and educational module) | Manual Input | Two-way communication | Multiple stages | Yes                                      |
| 2   | Diced Up Together             | A decision support tool for VAD decision and planning, designed to provide information and support to patients and caregivers. | Center for Medical Ethics & Health Policy at Skidmore College, NY, USA, and Hebrew College of Medicine with funding from Patient-Centered Outcomes Research Institute (PCORI) | 2015         | Houston, TX, USA | In use                      | Practitioner     | Website    | VAD (Decision Support Tool) No input | In between | One-way communication | Specific stage | Yes                                      |
| 3   | Harvi                         | An interactive simulation-based tool that helps patients and caregivers learn about pressure volume loops of the cardiovascular system and how various interventions impact these loops. | Daniel Busse, MD, PhD and Pamela Xas, LLC | 2016         | Columbus, OH, USA | In use                      | Practitioner     | website   | VAD (Decision Support Tool) No input | In between | One-way communication | Specific stage | Yes                                      |
| 4   | Heart Failure Stories         | An interactive simulation-based tool that helps patients and caregivers manage and monitor heart failure (HFrEF) symptoms, such as shortness of breath, swelling of extremities, and fatigue. The tool also allows patients to share their progress with a health practitioner. | Heart Failure Society of America, powered by the Health and the Fit, Inc. | 2017         | Bethesda, MD, USA | In use                      | Patients & caregiver      | Website    | VAD (Decision Support Tool) No input | In between | Multiple stages | Yes                                      |
| 5   | Heartmate III                | A comprehensive resource that provides up-to-date and evidence-based information on infectious diseases, drugs, and pathways, with a focus on the left ventricular assist device (LVAD) and its complications. | St. Jude Medical and Abbott | 2017         | Minneapolis, MN, USA | In use                      | Practitioner     | Android app | VAD (Decision Support Tool) No input | In between | One-way communication | Specific stage | No                                      |
| 6   | John Hopkins AABX Guide      | A comprehensive resource that provides up-to-date and evidence-based information on infectious diseases, drugs, and pathways, with a focus on the left ventricular assist device (LVAD) and its complications. | John Hopkins Medicine and Abbott | 2017         | Baltimore, MD, USA | In use                      | Practitioner     | Android app | VAD (Decision Support Tool) No input | In between | One-way communication | Specific stage | Yes                                      |
| 7   | LVAD Calc                     | A decision support tool for patients and caregivers, designed to help patients and caregivers manage and monitor heart failure (HFrEF) symptoms, such as shortness of breath, swelling of extremities, and fatigue. The tool also allows patients to share their progress with a health practitioner. | By Biotech Inc | 2014         | Southfield, MI, USA | In use                      | Practitioner     | iOS app    | VAD (Decision Support Tool) No input | In between | One-way communication | Specific stage | Yes                                      |
| 8   | LVAD@Home and LVAD@care      | A cloud-based home management system that allows patients to send clinical information and pump parameters to practitioners. LVAD@Care is a complementary monitoring application that allows practitioners to receive and monitor data from patients. | Kyushu University Graduate School of Medicine (Research Institute) | 2016         | Kitakyushu, Japan | In development phase | Patients & caregiver & Practitioner | Website    | VAD (Decision Support Tool) No input | In between | One-way communication | Multiple stages | No                                      |
| 9   | MyLVAD                        | A cloud-based home management system that allows patients to send clinical information and pump parameters to practitioners. LVAD@Care is a complementary monitoring application that allows practitioners to receive and monitor data from patients. | MyLVAD, MedStar Heart Institute, Washington Hospital Center | 2017         | Washington, D.C. | In use                      | Patients & caregiver | Website    | VAD (Decision Support Tool) No input | In between | One-way communication | Entire team | Yes                                      |
| No. | Name                          | Description                                                                 | Company / Founder / Sponsor | Last Updated | Location | Development Phase / Status | User / Audience | Platform | Purpose                  | Interactivity   | Communication   | Focus                  | Currently accessible to our research team? |
|-----|-------------------------------|-----------------------------------------------------------------------------|-----------------------------|--------------|----------|----------------------------|----------------|----------|--------------------------|----------------|----------------|----------------------|------------------------------------------|
| 10  | Qualia Health - Health Check | Helps users understand their physical, mental, and social health through a quick and fun health check. Originally designed with heart failure patients in mind, but now a consumer health app. It uses a combination of user input and ECG data to provide insights. | Qualia Health founded by Dr. David Feinberg, MD and Keith O’Gara | 2016 & 2017  | Chicago, IL, USA | In use          | Patients & caregiver | iOS App | Daily home monitoring | Manual input plus smart wearable input | Two way          | Entero journey      | Yes                                |
| 1  | ReliantHeart HeartResistRemote Monitoring | Remote patient monitoring works with the HeartResist™ VAD, providing a real-time view of the patient’s health through a series of sensors and data collection devices. | ReliantHeart, Inc. | 2017    | Houston, TX, USA | Investigational use in US, approved for use in Europe | Patients & caregiver and Practitioner | Website, app, hospital console | Daily home monitoring | Smart input | In between | Multiple stages | No                        |
| 12  | VAD Care App                  | VAD Care App provides daily status updates, allows for real-time communication, and offers a dashboard for patients and caregivers. | University of Michigan School of Nursing and Health Informatics | 2017 | Ann Arbor, MI, USA | In development (under clinical trial) | Patients & caregiver and Practitioner | App, Unspecified | Educational tool and daily home monitoring | Manual input | Two way          | Multiple stages | No                        |
| 13  | VADable                       | VADable allows doctors and patients to stay connected through a secure portal, providing real-time updates and alerts. | Mount Sinai Health System and Mount Sinai School of Medicine | 2016 | Los Angeles, CA and Palm Beach, FL, USA | In use | Patients & caregiver and Practitioner | iOS App | Daily home monitoring | Manual input | Two way          | Multiple stages | Yes                       |
| 14  | VADKids®                     | VADKids® is a home-monitoring app that allows patients and caregivers to track and monitor their VADs remotely. | Boston Children’s Hospital | 2018 | Boston, MA, USA | In pilot phase | Patients and caregiver (parents) | Smartphone | Educational tool and daily home monitoring | Manual input | Two way          | Entire journey | No                        |
| 15  | VADWatch® and Ailer® VADCare | VADWatch® and Ailer® VADCare provide real-time monitoring and alerts for VAD patients, allowing for timely intervention. | Ailer® Health Monitoring, Stanford Medicine | 2017 | Orlando, Florida, and Westport, CT, USA | In use | Patients & caregiver and Practitioner | Telemonitoring - unspecified | Daily home monitoring | Manual input | In between | Multiple stages | No                        |
| 16  | Vidscrip                      | A platform for doctors to share information and videos with patients. | John Brownlie and Brian Capp | 2017 | Minneapolis, MN, USA | In use | Patients & caregiver and Practitioner | Website, iOS and Android app | Educational | Manual input | In between | Multiple stages | Yes                        |
Table 4  Summarised patterns and themes in the data from Table 3.

| Last Updated | 2014 | 1 |
|--------------|------|---|
|              | 2015 | 1 |
|              | 2016 | 4 |
|              | 2017 | 10 |
| Location     | USA  | 14 |
|              | USA & Canada | 1 |
|              | Japan | 1 |
| Development phase / status | In Use | 13 |
|              | In Pilot Phase | 1 |
|              | In Development | 2 |
| User / Audience | Practitioner | 5 |
|              | Patients & Caregiver | 3 |
|              | Patients & Caregiver and Practitioner | 8 |
| Platform     | Website only | 2 |
|              | iOS app only | 4 |
|              | Android app only | 1 |
|              | Website & app (either platform) | 6 |
|              | Website, app and hospital console | 1 |
|              | Telemonitoring - unspecified | 1 |
|              | App - unspecified | 1 |
| Purpose      | DST (Decision Support Tool) | 2 |
|              | DST (Decision Support Tool) and educational | 1 |
|              | Educational | 4 |
|              | Daily home monitoring | 6 |
|              | Educational and daily home monitoring | 2 |
|              | Community support and educational | 1 |
| Interactivity | No input | 3 |
|              | Manual input | 11 |
|              | Manual input + smart wearable input | 1 |
|              | Smart input | 1 |
| Communication | One-way | 4 |
|              | In between | 6 |
|              | Two-way | 6 |
| Focus        | Specific Stage | 5 |
|              | Multiple Stages | 9 |
|              | Entire Journey | 2 |
| Currently Accessible? | Yes | 11 |
|              | No | 5 |