

Standing HC, Rapley T, MacGowan GA, Exley C.
[‘Being’ a ventricular assist device recipient: A liminal existence.](#)
Social Science and Medicine 2017, 190, 141-148.

Copyright:

© 2017. This manuscript version is made available under the [CC-BY-NC-ND 4.0 license](#)

DOI link to article:

<https://doi.org/10.1016/j.socscimed.2017.08.016>

Date deposited:

20/09/2017

Embargo release date:

19 August 2018



This work is licensed under a
[Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International licence](#)

‘Being’ a ventricular assist device recipient: A liminal existence

Standing, H. C¹., Rapley, T¹., MacGowan, G²³., and Exley, C⁴.

Author affiliations:

¹ Institute of Health and Society, Newcastle University, Newcastle Upon Tyne, NE2 4AX

² Department of Cardiology, Freeman Hospital, Newcastle Upon Tyne, NE7 7DN

³ Institute of Genetic Medicine, Newcastle University, Newcastle Upon Tyne, NE1 3BZ

⁴ Faculty of Health and Life Sciences, Northumbria University, Newcastle upon Tyne, NE1 8ST

Corresponding author: Holly Standing, Institute of Health and Society, Baddiley-Clark Building, Newcastle University, NE2 4AX, email: holly.standing@ncl.ac.uk

Abstract

Ventricular assist devices (VADs) are playing an increasing role in the management of heart failure. VADs are mechanical circulatory devices that support or replace the function of a failing heart. Currently, VADs are only offered in the UK to patients waiting for a heart transplant; however, the use of these devices is likely to increase in the near future. Presently, there is a dearth of literature exploring the day-to-day realities of living with a VAD, which will become increasingly important as the role of VADs is increased.

This paper adopts an interpretive phenomenological approach to uncover the experience of 'Being' a VAD recipient. Semi-structured interviews were conducted with 20 VAD recipients. The overarching theme is that life with a VAD is a liminal existence. This comprised four subthemes: the first examines how the VAD imposes limitations on recipients' lives that can precipitate a loss of identity; the second focuses on temporal disruptions, recipients' sense of time changes from authentic to inauthentic; the third explores how the VAD itself is liminal, it is positioned as temporary rather than as the 'answer' to the condition; and finally, we discuss VAD recipients' projections to the future and the possibility of an end to the experience of liminality.

Keywords: United Kingdom; ventricular assist device; heart failure; heart transplantation; phenomenology; liminality

Introduction

Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial (Turner 1969: 95).

This paper draws on the concept of liminality to discuss the experience of living with a Ventricular Assist Device (VAD). The concept of liminal states originates from cultural anthropologist Arnold Van Gennep (1960), who conceived it in relation to passage rites. It was further developed by Turner (1969), who coined the term 'liminality' to describe an ambiguous state which occurs following the loss of one social state without the development of another: a time of flux. Whilst its origins lie in anthropology, liminality is being increasingly used to aid our understanding of the experience of illness, in particular in relation to cancer where studies have highlighted a desire for normality and an awareness of the impossibility of returning to the pre-cancer normality (Balmer et al. 2015; Rees, 2016; Trusson et al. 2016). It is suggested that through a constant cycle of healthcare appointments illness can plunge us into a sense of temporal boundedness and liminality (Coventry et al. 2014). Relatedly, that liminality can be an enduring state that persists for the remainder of a person with cancer's life (Little et al. 1999). The concept of liminality is also suggested to provide insights into the way cancer survivors find themselves at the margins of everyday life (Blows et al. 2012). The concept has been applied to kidney transplant recipients, for whom liminality becomes particularly apparent when they attempt to re-enter 'normal life' and discover that the life offered by the transplant is not as expected (Crowley-Matoka, 2005).

Phenomenology and time

This paper focuses on the experience of time and identity following the implantation of a VAD. There is often a tendency for the temporal elements of chronic illness to be dismissed

(Gergel, 2013), and a need has been highlighted for health care professionals to develop a more nuanced understanding of patients' temporal experience (Shubin et al. 2015; Ellingsen et al. 2014). A review of experiences of time in chronic illness identified four structures, of which calendar or clock time is the most frequently used, which may lead us to believe that this has the greatest impact on the individual (Jowsey, 2016). However, Shubin et al. (2015) have problematized the tendency to focus on time as a linear form when attempting to understand the experiences of health and illness, they argue that time is often presented as something which is both consciously intelligible and easily manipulated by both the patient and the health care professional. Schutz (1962: 215-16) highlighted a need to distinguish the 'objective' time of clocks and calendar from 'inner time with which our actual experience (s) are connected with the past ... and with the future'.

Our study adopted a phenomenological perspective to explore time as experienced by VAD recipients. Phenomenology can offer a potential means of bridging the gap between medical and existential meanings of illness (Carel, 2011). Phenomenology aims to break through the taken-for-grantedness of daily experiences to expose the more fundamental lived meanings of the experience, to bring forward and make manifest what is normally hidden in human experience. Heidegger's major work, 'Being and Time', focuses entirely on the question of Being, of which time is a core component (Heidegger's, 1962). Heidegger sees human experience, identity and time as interwoven; we are temporally situated and our past, present and future are all experienced in unity. Our 'Being' is always relational, time cannot be understood as an external framework, it is central to our experience of the world. Further, our 'being-in-the-world' is always futural; we are always projecting towards the future and it is through our futural projections that we develop an understanding of ourselves (Shubin et al. 2015).

Ventricular assist devices

VADs are a form of mechanical circulatory support which are used increasingly to support patients with advanced heart failure on the waiting list for a heart transplant (NHS Blood and Transplant, 2015), they take over some or all of the pumping function of a patient's heart. There has been rapid development in VAD technologies over the past decade, which has led to a great expansion in the use of the devices (Emin et al. 2013). The VAD comprises of internal and external components. Internally there is the pump itself which is usually attached to the left ventricle, and externally there is a controller and batteries. Implantation requires major, open-heart surgery followed by a lengthy rehabilitation period. The VAD carries the risk of serious complications including bleeding and thrombosis, stroke, infection and device malfunction (Rogers, 2016). The VAD recipient, or their caregiver, are primarily responsible for day-to-day care of the device including: maintaining a constant power supply, cleaning and dressing the exit wound, and managing medications. This can result in significant changes to the lives' of the patients and caregivers (Kato et al. 2014). Previous research has highlighted the receipt of the VAD as a disruption to patients' sense of normality (Hallas et al. 2009; Ottenberg et al. 2014; Marcuccilli et al. 2013), which imparts significant changes to all aspects of life (Sandau et al. 2014).

This paper explores the experiences VAD recipients in the UK under the indication of bridge to transplantation (BTT). Presently, in the UK, VADs are only commissioned as a BTT or bridge to myocardial recovery (NHS Commissioning Board, 2013). Under BTT the device is used to sustain individuals eligible for transplantation until a donor heart becomes available. Bridging to myocardial recovery is where the device is used to relieve strain on the heart affording the possibility that it may recover sufficiently for the device to be explanted, however, this is a rare outcome achieved by less than 4% of a UK sample (Özalp et al. 2014). In the US, and much of Europe, VADs are also used for long-term support, known as

destination therapy (DT). This is particularly prevalent in the US where it accounts for over 40% of all VADs implanted (Kirklin et al. 2014).

Our understanding of the ways in which medical technologies intervene into our lives is limited (Haddow et al. 2015; Lauritzen and Hydén, 2007). Medical technologies, like the VAD, originate from the world of medicine as such their aims and rationality are developed in this domain and do not necessarily correspond with the life-world of the patient (Lauritzen and Hydén, 2007). A role for phenomenology has been indicated in understanding and evaluating new technologies (Svenaesus, 2007; 2013). This paper uses the lens of Heidegger's phenomenology to explore the meaning of 'Being' a VAD recipient, to uncover the implications of the device for recipients' life-worlds.

Methods and Methodology:

Design

The data presented in this paper formed part of a PhD study conducted in the UK between 2012-2015. This study adopted an interpretive phenomenological approach based on Heidegger (1962) to explore the experience of 'Being' a VAD recipient. Phenomenology is an appropriate methodology for the investigation of phenomena that are central to the lived experience of human beings but not well understood (Carpenter, 1995). Further, it focuses on human experience as a topic in its own right (Langdrige, 2007). In order to understand an aspect of human experience, phenomenological researchers borrow the descriptions of others allowing them to become more vicariously experienced in the phenomenon (Van Manen, 1984; Giorgi, 1997).

Procedure

Ethical approval for the study was granted by Newcastle and North Tyneside 1 NHS Ethics Committee (Reference: 12/NE/0218).

Participants were recruited via a VAD implanting centre in the UK. Clinicians involved in the care and management of VAD patients were used as gatekeepers. They identified potential participants and sought consent for the researcher to make contact. Interviews were scheduled at a time and location of the participants choosing. Participants were given the opportunity to withdraw from the study at several time points during the recruitment process. Each interview was initiated with the question ‘please tell me a bit about the process by which you came to receive a VAD?’ The intention of this approach was to elicit a brief synopsis of the individual’s medical history that had culminated in the implantation of the VAD. This narrative approach afforded respondents the opportunity to give the history of their illness in their own words, focusing on particular events that were key to them. Such an approach is in line with the phenomenological basis of the study, which focuses on the lived experience of the individual (Finlay, 2008). Participants’ stories often highlighted interesting issues that had not been anticipated, these were often explored with later questions. Responses to this question were varied; whilst some respondents were relatively brief, others spoke uninterrupted without the need for prompts for up to 10 minutes. In total interviews lasted between 39 and 105 minutes.

A purposive sample of 20 VAD recipients, and 11 partners, were included in the study. Participants were eligible for participation in the study if they were living with, or had previously lived with a VAD. The majority of patients were implanted with the HeartWare® II left ventricular assist device, which is a third generation continuous flow device.

Several purposive sampling approaches (Patton, 1990) were utilised to ensure that a range of experiences living with the VAD were included in the study. Typical case sampling was employed in the first round of recruitment; clinicians were asked to identify individuals who they perceived to represent a typical VAD recipient. Critical case sampling was employed as the study progressed in order to identify individuals who possessed specific characteristics, these were highlighted by the research team to test emerging themes. Attempts were also made to ensure that the sample demonstrated a range of experiences life with a VAD, and was representative of the wide geographical area covered by the implanting centre. Table 1 provides demographic characteristics of the study sample.

Data analysis

Data analysis was informed by the interpretive phenomenological methodological basis of the study. Data collection and analysis occurred concurrently throughout the study. Analysis involved the processes of highlighting and line-by-line coding (Van Manen, 1984); these two approaches serve different functions in the search for meaning, and ask different questions of the data. During the highlighting stage the data is interrogated by asking ‘what statements or phrases seem particularly essential or revealing about the experience being described?’, whereas during line-by-line coding every sentence is interrogated to ascertain what it can reveal about the phenomenon of interest. Initial analysis involved a close reading of the transcripts whilst attributing a code to each segment of the text, this could be a word, line, or section of text, and each segment could have more than one code attributed to it. Writing formed a major component of the analysis, facilitating the uncovering of essences of phenomena through engagement with the hermeneutic cycle. This involved a cyclical process of reading, reflective writing and interpretation (Laverty, 2003). Reflective writing and rewriting allows us to try and capture the complexity and ambiguity of the lived world being described (Finlay, 2008).

Several credibility measures were employed. These included a continuous process of review and discussion of emerging themes with supervisors and peers. Although we did not engage in member checking (Lincoln and Guba, 1985), emerging themes were discussed in subsequent interviews and the final themes were discussed with specialist clinicians who had acted as gatekeepers to the study, who reflected that the findings were in line with their own experiences of working with this group.

Findings

The overarching theme of this paper is that ‘Being’ a VAD recipient is a liminal existence. Liminality as a lens for understanding the experience of this group emerged from the interviews themselves.

Receipt of the VAD creates liminal identities

Phenomenology understands the body as the core of our existence, when something goes wrong with the body this can affect human existence as a whole (Carel, 2011). As noted by Frank (1991) ‘when the body breaks down, so does my life’ (10). VAD implantation is a major disruption to the body involving open heart surgery, and the joining of the body to a mechanical object. The current generation of VADs are quite cumbersome, with their internal and external components, as such physicality of the device itself imparts limitations on the recipient.

I actually went to my first rugby match since I took ill on Sunday, so I’m starting to slowly reintroduce what I used to do. I was a bit nervous at first, but actually it wasn’t too bad ... I’m still in the mind set of ‘I’m normal’ and I want to go out and do the things that I want to do ... for my friend’s stag party they’re going go-karting and paintballing, I can’t do those things, and those were the things I would have done in the past. Rather than watch

the rugby I used to play rugby, the same with the American football, now days I have to be content with watching it, so it's kind of a whole different thing. (*Jack, 3 years on VAD support*)

By attending the rugby match Jack appears to be trying out his old identity, that of rugby player and fan, to see whether this fits with his new life and body. However, this sparked the realisation that he was no longer 'normal'. The world of rugby, of which he had been part, still exists but it no longer makes sense to him in the way it did before; it has become 'uncanny and un-homelike' (Svenaesus, 2011: 341). Life following the implant of the VAD is significant change from Jack's pre-illness life and involves a loss of previously valued hobbies and interests. The physicality of the VAD, and the necessity of protecting it, act as a barrier to these activities and a reminder of the vulnerability of his condition, and his dependence on the device to live. Heidegger's (1962) conception of 'Being' is always being-towards-death. However, it is not only our physical demise to which Heidegger refers, but also a breakdown in meaning that strips our ability to understand and make sense the world and ourselves (Aho, 2016). Familiar aspects of the world can collapse into meaningless.

In addition to the loss of hobbies which previously formed a key aspect of our identity, the VAD may cause other meaningful elements of identity to collapse, such as the ability to take on family roles and responsibilities.

I can't play with the bairn [child] properly, she can't jump on us, stupid little things, it's the small things that you wouldn't have thought would get to you that do (*Michael, 6 months on VAD support*)

Life with the VAD can involve a loss of basic aspects of daily life that may previously have been taken for granted, such as being able to physically play with your child, resulting in a sense that life has become unfamiliar and unhomelike. Svenaesus (2011) highlights the

‘otherness’ than can occur when the lived body takes on alien qualities during illness: ‘Illness is an unhomelike being-in-the-world in which the embodied ways of being-in of the self (person) have been thwarted’ (ibid. 237). Implantation of the VAD may lead to loss of identity, recipients’ way of being-in and making sense of the world is disrupted.

Temporal disruption of the VAD

Heidegger’s phenomenology understands life to be a fully temporal experience (Papadimitriou and Stone, 2011), where experience identity and time are inextricably linked (Gergel, 2013). Interviewees indicated that the VAD had disrupted their experience of time, and the natural flow of their lives.

It’s awful, it’s an awful feeling you being stuck ... at this crossroads you can’t go anywhere, it’s like you being in a telephone box and not being able to get out. (*Jan, 4 years on VAD support*)

Jan’s metaphorical feeling of being stuck indicates a sense of ‘boundedness’ in space and time. She perceives that she has no control over the direction or flow of her life; she is projecting towards, and hoping for, a heart transplant but she has little to no control over the attainment of this outcome, it is dependent upon suitable organ being found. As a result, she feels that her life is ‘stuck’ or on hold. The disruption of chronic illness has been suggested to cause time to stand still, and the past and future to converge into a ‘stagnating present’ (Toombs, 1990: 237). This sense of being stuck in time and place is at odds with our natural orientation to the world. To live is to be in a state of continuous change, without the passage of time everything is fixed in the moment, much like a photograph where nothing moves or changes the subject in the picture may provide an illustration of life but it is not life itself (Ellingsen et al. 2014). For VAD recipients a sense of liminality may arise from the lack of control that they have over the attainment of their desired future.

Many of the interviewees indicated that they avoided making plans for the immediate future with the VAD, but postponed these for a future post-VAD.

Matt: We're in the process also of buying a VW camper, an old camper and Susie'll say 'it's not the right time, it's not the right time', but when is the right time, you know what I mean?

Susie [Matt's wife]: What we've always said, is after your transplant weren't it but...

Matt: But it could be another couple of years, that. (*Matt, 2 ½ years on VAD support*)

Even Matt, a stable and established VAD recipient, who appeared to have accepted the VAD into his life to the extent that he considered it to be 'part of him', reported putting off life events whilst living with the device. The ability to make plans is thought to be critical to our subjective experience of agency, allowing us to manipulate and modify our experience of time (Flaherty, 2003). Our natural state is not to passively allow time to happen to us, but to modify some temporal dimensions of our lives (Flaherty, 2011). However, we should note that for Matt and his wife, the heart transplant was seen as something that will definitely happen; it may take several years, but it will happen eventually, their plans are on hold until it does.

Recipients' sense of 'boundedness', or being stuck, may also be reinforced by the care taking work required by the VAD. In particular, by the need to maintain a constant power supply to the device through batteries, or remaining in close proximity to a mains electricity supply. Ill people can become stuck in anticipation of the next moment of medical work (Little et al, 1998; Morris, 2008). This marks a move away from what Heidegger calls authentic time, which is projecting to the future, towards inauthentic time which is concerned with biological

demands. Heidegger sees our 'being-in-the-world' as always futural. It is through our futural projections that we develop an understanding of ourselves (Shubin et al. 2015).

My attitude on life changed completely when I got this [VAD] fitted, it's like you take each day as it comes, you get out of bed in the morning you feel well, you get through that day and you see what the next day's going to bring because you never get two days the same. One day can be fantastic and you can spring clean your house or you can walk for miles, you can do anything. The next day you can't get out of your chair. It's swings and roundabouts. (*April, 3 years on VAD support*)

The unpredictability of her condition with the VAD necessitates that April takes each day as it comes. Her condition lacks stability. Similar, impacts are reported amongst patients with cancer who avoid making plans for more than a few weeks in the future (Bamler et al. 2015). This unpredictability and focus on day-to-day fluctuations in functioning may also act as a constant reminder of their transitional state (Gardner, 1998), reminding recipients of their precarious position and the fact that they are waiting for a transplant.

The VAD as a liminal object

The VAD itself, as a piece of technology and a treatment, can also be conceived of as a liminal object. Due to commissioning limitations in the UK, from its first introduction by clinicians the device is presented temporally, it is an interim measure (NHS Commissioning Board, 2013). This appears to profoundly influence recipients' orientation to life with the device, it is seen as a temporary state and a stopgap until a donor heart can be found, rather than 'the answer' to their condition. Moreover, the device appears to be only acceptable in this role; the VAD is endurable until a transplant can be achieved, but it was not a feasible long-term solution.

Provided it [heart transplant] is going to happen eventually you just keep on day-to-day with just getting on with life ... it's [the VAD] keeping me alive until such time as I can get the heart transplant. (*Russell, 2 ½ years on VAD support*)

Life with the device is liminal time, which has been described as time spent waiting for a new and improved state (Gardner, 1998). For many the heart transplant appears to be a necessary motivation for enduring the perceived limitations of the VAD.

I think while the hope's there of a new heart then you put up with this [the VAD], you deal with all the nonsense and everything else, if somebody said 'that's all you're going to get' that would be just...I can't even contemplate that. (*Terry partner of Jan, 4 years on VAD support*)

For Terry, the idea of his partner Jan spending the rest of her life with the VAD was beyond comprehension. Life conferred by the VAD was untenable in the long term. However, low rates of heart transplantation in the UK mean all VAD recipients BTT are unlikely achieve this outcome (MacGowan et al. 2011). Further, the VAD itself has implications for their position on the transplant waiting list, those stable on VAD support are not considered urgent cases and the presence of the VAD also complicates and reduces the likely success of the transplant operation (Ciarka et al. 2015; Takeda et al. 2015). Interviewees demonstrated limited understanding of these factors. The unfortunate reality is that many VAD recipients will never receive a transplant, but will die on VAD support, be that after a period of several months or years. For the majority the VAD is not the temporary measure it is assumed to be. Further, medical technologies can present patients with new uncertainties (Lauritzen and Hydén, 2007). Indeed, as the VAD is a relatively new technological development, it carries uncertainties in terms of its longevity.

Well this [VAD] has got a life expectancy, which I think is 3 years then after that you're hitting problems in various shapes and forms ... I understand that VADs in the States are getting up to six or seven years ... but I don't know if that's the case here... I think they've only kind of got people for about 4 years or something here at the moment. (*Gordon, 1 ½ years on VAD support*)

Many interviewees had developed expectations about the longevity of the device, and the likelihood and timeframe for experiencing problems. Concerns were apparent about the perceived lack of recourses available to them should the device fail. Although Gordon had only been on VAD support for a year and a half, the life expectancy of the device and the lack of success he perceived around secondary implants were already causing him concern.

Projections to the future

Unsurprisingly, given the presentation of the device as a BTT, the majority respondents made sense of the time with the device by looking forward to a future with a heart transplant. The transplant was seen as imparting fewer limitations on their lives, and offering the potential for greater health and physical functioning than the VAD.

You see people post-transplant who just seem to be really completely back to where they were... I suspect I would probably be a bit fitter or could get a bit fitter than I seem to be able to do with the VAD. (*James, 11 months on VAD support*)

For James, the perceived limitations of the VAD prevented him from returning to his prior level of functioning. This is true to an extent, his third generation VAD was a continuous flow device meaning it did not respond to the exertion of exercise in the same way as a human heart. Furthermore, many sports and types of physical activity are incompatible with

the physicality of the device. James appeared to view the post-transplant future self as a return, or at least a closer approximation, to his pre-illness self. As with the majority of the interviewees the limitations of transplantation tended to be neglected or dismissed.

Interestingly, in spite of the VAD being fitted as a BTT there were some respondents who expressed a preference for remaining on VAD support rather than have a transplant.

Maybe at the moment even I would prefer it [the VAD] to a heart transplant 'cos those can be obviously risky, can't they, with rejections and things. If I was to get rid of it then that would be great ... I wouldn't want to go through that [operation and pain] again unnecessarily. (*Paul, 4 months on VAD support*)

Paul's preference, although hedged, was to live with the VAD as long as possible before undergoing a heart transplant, which he viewed as major risk that he wished to avoid if possible. The limitations conferred by the VAD were perceived as minor irritations which could be endured for the foreseeable future compared to the potentially life-threatening risks of the heart transplant. Any potential benefits to functioning offered by the heart transplant failed to outweigh these risks; maintaining the status quo was preferable unless, or until, the heart transplant became an absolute necessity. Preference for a familiar treatment over an unfamiliar has also been observed amongst patients with kidney failure who choose to remain on dialysis over transplantation (Crowley-Matoka, 2005). Paul, however, had only been living with the VAD for a couple of months which had been relatively free of complications, his attitude towards the VAD, and the perceived limitations of the device may change as time stretches on.

Expectations and projections to the future were not static, but appeared to fluctuate as time spent living with the device stretched on. For many, it appeared that hopes of achieving transplantation reduced and receded as time with device increased.

We've been on the pump for so long we'd almost sort of talked ourselves out of it [transplant] ... And the VAD was going to be the way forward forever and ever and ever...we thought we're not going to get a transplant, you know we're living with the VAD, and we'd got our heads around living with the VAD. (*Fred, 3 years on VAD support*)

The longer Fred lived with the VAD the less likely he perceived his chances of a heart transplant. His conception of life with the device changed; the VAD became normality. This was a new and different normality, but it was one that he accepted, at least for the foreseeable future; life with the VAD was no longer seen as liminal. However, this new normality itself was unstable, and had recently been disrupted by the development of a potentially life-threatening infection, and him being listed on the urgent transplant waiting list. It appears that any normality that VAD recipients may achieve is unstable, it can breakdown unexpectedly and drastically. As such, the liminality experienced by VAD recipients may be best conceived not as a state in itself, but rather the loss of a fixed state.

As discussed above, presentation of the device as a BTT meant many of the interviewees projected towards and expected to receive a heart transplant. However, it is unclear whether heart transplantation itself offers an end their liminality.

The only thing I worry about is it [transplant] going to be ok, and how long is it going to last...because when it comes to a transplant it's, I think on average it's about 10-15 years, something like that but it's kind of like how long is a piece of string... my main worry is how long is it going to last? I

want to see my nephew grow up, and obviously I want to get married, I want to have maybe have kids of my own, but I kind of think what's held us back from doing that is, I don't want to sort of like have kids and then God forbids something happens. (*Jack, 3 years on VAD support*)

Jack was one of few interviewees to recognise the limitations of transplantation. He recognised that a heart transplant does not mean he will be healthy and normal again, but rather it will be a continuation of the uncertainty. Life expectancy at five years for heart transplant recipients is 72.5% (Lund et al. 2014). For Jack, the persistent uncertainty about whether he has a long term future held him back from important life events that many of us would take for granted. For VAD recipients, all futures which they may project towards are temporary. A degree of liminality is likely to persist for the rest of their lives; they will always be under its lingering shadow. This pervading sense of liminality is key to the experience of 'Being' a VAD recipient.

Discussion

We propose that the life-world of individuals living with VADs as a BTT is characterised by a state of persistent liminality. Implantation of the device breaks down the recipients' previous way of being-in-the-world, causing their life-world to become what Sevneaus (2000) calls 'uncanny and unhomelike', and highlighting the structural vulnerability that lies at the core of our identities (Aho, 2016). The majority of these VAD recipients viewed life with the device as a temporary state, projecting towards a future without the VAD. Moreover, for most the VAD is only acceptable in this role as a stopgap, echoing previous studies which suggest that whilst the VAD is experienced as a relief, transplantation is viewed as the cure (Overgaard et al. 2011). However, the recipients themselves have no control over the attainment of this outcome, resulting in the sense that life spent living with the device is stuck

or on hold. This sense of being stuck in time is at odds with our natural state of being-in-the-world which is to always be moving forwards (Ellingsen et al. 2014). The VAD itself demands attention, its needs must become a central feature around which recipients' lives and time is organised; failure to do so is to risk their life. This aspect of the experience appeared to be deeply distressing and frustrating for the VAD recipients.

The sense of liminality is compounded by the uncertainty that surrounds all futures that the VAD recipients may project towards, and indeed whether they really have a future at all. Illness is said to disrupt and interrupt the taken-for-granted world, shattering illusions that life is predictable and linear and our unquestioning faith in the idea that we have a tomorrow (Kierans, 2005). Likewise, for some of the VAD recipients there is concern about whether they have a future for which to plan. Guidry-Grimes and Sederstrom (2015) suggest that the experience of suffering can impair the ability to consider possible futures; they illustrate this by drawing on Halpern's (2001) insight:

The problem for people who are suffering is not just that they cannot imagine future goals that are several steps away, but that they also lack enough security and comfort to feel a sense of ongoingness into the immediate future (112).

We suggest that the liminality experienced by VAD recipients is not a transient state, but is likely to be present for the remainder of their lives; recipients must learn to live under its lingering shadow. Whilst previous VAD literature has touched on the concept of liminality (Guidry-Grimes and Sederstorm, 2015; Overgaard et al. 2011), this is the first paper to highlight liminality as the essence of the experience of being BTT with these devices.

Implications for practice

This paper outlines the disruption that VAD can cause to recipients' sense of time, and their way of being-in-the-world. It is suggested that accounting for the implications of chronic

illness on time can offer us the opportunity to develop a better understanding of the complexities of the experience, as well as aiding the development of more tailored suggestions for effective self-management (Jowsey, 2016). Indeed, we believe this paper will be of interest not only to sociologists but to health care professionals involved in the care of VAD recipients. Svenaeus (2011) suggests that the role of the health care professional should be to understand the un-homelike being-in-the-world of the ill individual and bring it back to home-likeness again.

The accounts of VAD recipients reported in this paper raise questions about the appropriateness of BTT when rates of heart transplantation are so low in the UK. The likelihood of a VAD recipient receiving a heart transplant is remote; as such, BTT is essentially DT for the majority (Howell and Lim, 2015). Of 102 VAD recipients implanted at a UK centre between 2009 and 2013, only 14 were transplanted, with only three of these occurring within the first 6 months of VAD support (Özalp, et al. 2014). Given the realities of transplantation in the UK, it appears logical, and moreover ethical, to refocus on the device as a long-term treatment option. Clinicians need to be cognizant of the impacts of the VAD on recipients' temporality, as discussed in this paper, and learn to frame the device in a manner which allows for consideration of multiple futures as opposed to a sole focus on transplantation.

Further, presentation of the VAD as BTT which implies the possibility of transplantation may mean recipients are less inclined to accept the device, and its limitations. Acceptability of treatment options has been linked to the existence of alternatives (Lehoux, 2004). However, the view of either the VAD or transplantation as the 'answer' is problematic, neither actually offers a cure for the condition (Takayama et al. 2014). Organ transplantation requires lifelong dependence upon immunosuppressants (Rady and Varheijde, 2014), which themselves carry unpleasant and potentially life-threatening side effects. Those interviewed in this study

demonstrated limited awareness of these issues, as has been reported previously (Modica et al. 2015).

MacGowan et al. (2015) have proposed changes to the transplant listing criteria to deal with this disparity between those BTT and heart transplant numbers. It is proposed that VAD recipients who are ambulatory and at home should be 'registered' at the transplant centre, but not actively placed on the transplant list; this would result in a more transparent policy, where there is a strong intention for those actively listed to be transplanted (ibid.). Reducing the number of individuals with VADs as BTT would also free up resources to be directed towards DT. In the UK, expanding the use of VADs to include DT has been supported by NICE guidance (NICE, 2015). It is estimated that 1,000 patients a year would benefit from DT, however it is suggested that commissioners perceive the cost of the device as prohibitive and 'palliative care and early death are much cheaper' (Westaby, 2015: 48). Indeed, VADs breach the current accepted threshold of £20,000 to £30,000 per quality adjusted life year (QALY), coming in at £53,527/ QALY (Clarke et al. 2014). Although they may fall within willingness-to-pay thresholds that can be applied to end of life criteria (Patel et al. 2016). Greater transparency regarding the chances of transplantation is likely to facilitate recipients in accepting life with the device, and reduce the experience of liminality.

Strengths and limitations

Participants were recruited for this study via clinician gatekeepers. Attempts were made to include as wide a range of experiences with the VAD as possible; purposive sampling was used to seek individuals with certain characteristics or experiences that would test themes emerging from the data. However, gatekeepers had ultimate control over who was approached regarding participation. As such, there may be individuals who could have provided interesting insights into the experience of 'Being' a VAD recipient who were not

sampled in this study. Future research would benefit from utilising a range of methods to promote recruitment to ensure that a wide range of individuals are sampled.

As participants were recruited from a single setting, it is possible that the experience of living with a VAD differs for individuals based at different hospitals due to varying levels of support or resources. The site used in this study is an established implanting centre which has one of the largest numbers of VAD patients in the UK (NHS Blood and Transplant, 2015). As such, the experience of those under the care of this established team may differ from those at smaller or newer implanting centres.

We focused specifically on uncovering the experience of individuals BTT with a VAD, as such the findings of this study are likely to be limited to the UK. The experiences described in this paper are closely tied to the concept of BTT and may not be applicable to those on DT. Indeed, previous research suggests differences between those BTT and those with VADs as a DT (Modica et al. 2015). Furthermore, they may be limited to a UK sample as there are disparities in levels of transplantation for those BTT, in the US 37% of patients BTT received a transplant within a year (Kirklin et al. 2014), compared to 13% of UK patients in a 4-year sample (Özalp et al. 2014).

Partners were present in 11 of the 20 interviews conducted. This was an intentional aspect of the study design. Whilst it was recognised that utilising dyadic interviews might curtail participants' responses, it was felt that this would be the most appropriate manner of ensuring that respondents felt comfortable in the research process. Furthermore, it was acknowledged that the experience being sought, that of 'Being' a VAD recipient, does not occur in isolation, it is experienced within the context of peoples' lives. Heidegger's phenomenology states that people are not detached; they make sense of their world from within it, and there is no preference from a Heideggerian perspective for one-on-one over dyadic interviews (Taylor

and de Vocht, 2011). Although allowing partners to be present in interviews will have influenced the accounts of 'Being' a VAD recipient, this is not necessarily a limitation of the research.

Conclusion

This paper has highlighted the profound influence that commissioning restrictions and presentation of VADs as a BTT has on VAD recipients' perceptions of the device. For the VAD recipients in this study, the device was not viewed as the 'answer' to their condition.

The life afforded by the device is temporary; for many recipients this is a source of great frustration. Any 'new normal' that the recipient may develop is temporal. It is unstable and uncertain and may break down without any warning; the recipient's life is still precarious.

Life with a VAD is an extended acute phase. This extended liminality is part of the essence of 'Being' a VAD recipient.

References

Aho, K. A. (2016). 'Heidegger, ontological death, and the healing professions', *Medicine, Health Care and Philosophy*, 19, 55-63.

Balmer, C., Griffiths, F., & Dunn, J. (2015). A 'new normal': Exploring the disruption of a poor prognostic cancer diagnosis using interviews and participant-produced photographs. *Health*, 19(5), 451-472.

Blows, E., Bird, L., Seymour, J. and Cox, K. (2012) 'Liminality as a framework for understanding the experience of cancer survivorship: a literature review', *Journal of Advanced Nursing*, 68(10), 2155-2164.

- Carel, H. (2011). Phenomenology as a resource for patients. *Journal of Medicine and Philosophy*, 37(2), 96-113.
- Carpenter, D. (1995) 'Phenomenological research approach', in Streubert, H.J., & Carpenter, D. (ed.) *Qualitative Research in Nursing: Advancing the Humanistic Imperative*. Philadelphia: J. B. Lippincott, 29-49.
- Ciarka, A., Edwards, L., Stenhilk, J. and Lund, L. (2015) 'Association between age, bridge to transplant continuous flow LVAD use, and outcomes after heart transplantation', *The Journal of Heart and Lung Transplantation*, 34 (4), S82.
- Clarke, A., Pulikottil-Jacob, R., Connock, M., Suri, G., Kandala, N-B., Maheswaran, H., Banner, N. R., and Sutcliffe, P. (2014) 'Cost-effectiveness of left ventricular assist devices (LVADs) for patients with advanced heart failure: Analysis of the British NHS bridge to transplant program', *International Journal of Cardiology*, 171 (3), 338-345.
- Coventry, P. A., Dickens, C., & Todd, C. (2014). 'How does mental–physical multimorbidity express itself in lived time and space? A phenomenological analysis of encounters with depression and chronic physical illness.' *Social science & medicine*, 118, 108-118.
- Crowley-Matoka, M (2005) 'Desperately seeking 'normal': the promise and perils of living with kidney transplantation', *Social Science and Medicine*, 61, 821-831.
- Ellingsen, S., Roxberg, A., Kristoffersen, K., Rosland, J. H., Alvsvag, H. (2014) 'The experience of time at the place, when living with severe incurable disease- A phenomenological study', *Scandinavian Journal of Caring Sciences*, 28 (3), 458-468.
- Emin, A., Rogers, C. A., Parameshwar, J., MacGowan, G., Taylor, R., Yonan, N., Simon, A., Tsui, S., Schueler, S. and Banner, N. R. (2013) 'Trend in long-term mechanical circulatory

support for advanced heart failure in the UK', *European Journal of Heart Failure*, 15, 1185-1193.

Finlay, L. (2008), "Introducing phenomenological research", [Online] Available at: www.lindafinlay.com/introducingphenomenologicalresearch.doc (Accessed 19 April 2012)

Flaherty, M. G. (2003). Time work: Customizing temporal experience. *Social Psychology Quarterly*, 17-33.

Flaherty, M. G. (2011). *The textures of time: Agency and temporal experience*. Temple University Press.

Frank, A. W. (1991) *'At the Will of the Body: Reflections on Illness'*, Boston: Houghton Mifflin.

Gardner, G. (1998). 'The human dimension of nosocomial wound infection: a study in liminality', *Nursing Inquiry*, 5 (4), 212-219.

Gergel, T. L. (2013). 'Illness perception, time perception and phenomenology—an extended response to Borrett.' *Journal of evaluation in clinical practice*, 19(3), 501-508.

Giorgi, A. (1997) 'The theory, practice, and evaluation of the phenomenological methods as a qualitative research procedure.', *Journal of Phenomenological Psychology*, 28(2), 235-260.

Guidry-Grimes, L. and Sederstrom, N. (2015) 'Expectation and suffering with LVAD deactivation', *The American Journal of Bioethics*, 15 (7), 74-76.

Haddow, G., King, E., Kunkler, I., & McLaren, D. (2015). 'Cyborgs in the everyday: Masculinity and biosensing', *Science and Culture*, 24 (4), 484-506.

- Hallas, C., Banner, N, R. and Wray, J. (2009) 'A qualitative study of the psychological experience of patients during and after mechanical cardiac support', *Journal of Cardiovascular Nursing*, 24 (1), 31-39.
- Halpern, J. (2001) '*From detached concern to empathy: Humanizing medical practice*', New York: Oxford University Press.
- Heidegger, M. (1962). *Being and time*, trans. J. Macquarrie and E. Robinson.
- Howell, N. J., & Lim, H. S. (2015). Ventricular assist device: destination UK.
- Jowsey, T. (2016) 'Time and chronic illness: a narrative review', *Quality of Life Research*, 25 (5), 1093-1102.
- Kato, N., Jaarsma, T., & Gal, T. B. (2014). Learning self-care after left ventricular assist device implantation. *Current heart failure reports*, 11(3), 290-298.
- Kierans, C. (2005) 'Narrating kidney disease: The significance of sensation and time in the emplotment of patient experience', *Culture, Medicine and Psychiatry*, 29 (3), 341-359.
- Kirklin, J. K., Naftel, D. C., Pagani, F. D., Kormos, R. L., Stevenson, L. W., Blume, E. D., ... & Young, J. B. (2014). Sixth INTERMACS annual report: a 10,000-patient database. *The Journal of Heart and Lung Transplantation*, 33(6), 555-564.
- Langdrige, D. (2007) '*Phenomenological psychology: Theory, research and methods*', London: Pearson.
- Lauritzen, S. L., Hydén, L-C. (2007) '*Medical Technology and the Life World*', Oxon: Routledge.
- Laverty, S.M. (2003) 'Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations', *International Journal of Qualitative Methods*, 2(3), 21-35.

- Lehoux, P. (2004) 'Patients' perspectives on high-tech home care: a qualitative inquiry into the user-friendliness of four technologies', *BMC Health Services Research*, 4-38.
- Little, M., Jordens, C. F., Paul, K., Montgomery, K. and Philipson, B. (1998) 'Liminality: A major category of the experience of cancer illness', *Social Science and Medicine*, 47 (10), 1485-1494.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry* (Vol. 75). Sage.
- Lund, L. H., Edwards, L. B., Kucheryavaya, A. Y., Benden, C., Christie, J. D., Dipchand, A. I., Dobbels, F., Goldfarb, S. B., Levvey, B. J., Meisser, B., Yusen, R. D., Stehlik, J., (2014) The registry of the International Society for Heart and Lung Transplantation: thirty-first official adult heart transplant report- 2014; focus theme: retransplantation, *Journal of Heart and Lung Transplantation*, 33 (10),996-1008.
- MacGowan, G. A., Parry, G., Schueller, S. and Hasan, A. (2011) 'The decline in heart transplantation in the UK', *British Medical Journal*, 342.
- Marcuccilli, L., Casida, J. and Peters, R. M. (2013) 'Modification of self-concept in patients with a left-ventricular assist device: an initial exploration', *Journal of Clinical Nursing*, 22 (17-18), 2456-2464.
- Modica, M., Ferratini, M., Torri, A., Oliva, F., Martinelli, L., De Maria, R. and Frigerio, M. (2015) 'Quality of life and emotional distress early after left ventricular assist device implant: A mixed-methods study', *Artificial Organs*, 39 (3), 220-227.
- Morris, D. (2008) 'Diabetes, chronic illness and the bodily roots of ecstatic temporality' *Human Studies*, 31 (4), 399-421.
- NHS Blood and Transplant (2015), 'Annual report on ventricular assist devices', Available online: www.odt.nhs.uk/pdf/nhsbt_annual_vad_report.pdf (Accessed 22nd August 2015)

NHS Commissioning Board (2013) '2013/14 NHS standard contract for ventricular assist devices (VADs) as a bridge to heart transplantation or myocardial recovery' Available at: <http://www.england.nhs.uk/wp-content/uploads/2013/06/a18-vad-all.pdf> (Accessed 10th August 2014)

NICE (2015) 'Implantation of a left ventricular assist device for destination therapy in people ineligible for heart transplantation' Available at: <https://www.nice.org.uk/guidance/ipg516> (Accessed: 23rd September 2015)

Ottenberg, A. L., Cook, K. E., Topazian, R. J., Mueller, L. A., Mueller, P. S., & Swetz, K. M. (2014). Choices for Patients "Without a Choice". *Circulation: Cardiovascular Quality and Outcomes*, 7(3), 368-373.

Overgaard, D., Kjeldgaard, G. H. and Egerod, I. (2011) 'Life in transition: A qualitative study of the illness experience and vocational adjustment of patients with left ventricular assist device', *Journal of Cardiovascular Nursing*, 27 (5), 394-402.

Özalp, F., Bhagra, S., Bhagra, C., Butt, T., Ramesh, B., Robinson-Smith, N., Wrightson, N., Parry, G., Griselli, M., Hasan, A., Schueler, S. and MacGowan, G. (2014) 'Four-year outcomes with third-generation centrifugal left ventricular assist devices in an era of restricted transplantation', *European Journal of Cardio-thoracic Surgery*, 46 (3), 35-40.

Papadimitriou, C., & Stone, D. A. (2011). Addressing existential disruption in traumatic spinal cord injury: a new approach to human temporality in inpatient rehabilitation. *Disability and rehabilitation*, 33(21-22), 2121-2133.

Patel S, Nicholson L, Cassidy CJ, and Wong, K, Y-K. (2016) Left Ventricular Assist Device: A Bridge to Transplant or Destination Therapy, *Postgraduate Medical Journal*, Published Online First: [13th December 2016] doi:10.1136/postgradmedj-2015-133718

- Patton, M. Q. (1990). *Qualitative evaluation and research methods*. Thousand Oaks: SAGE Publications, inc.
- Rady, M. Y. and Verheijde, J. L. (2014) 'Ethical challenges with deactivation of a durable mechanical circulatory support at the end of life: Left ventricular assist device and total artificial hearts', *Journal of Intensive Care Medicine*, 29 (1), 3-12.
- Rees, S. (2016). 'Am I really gonna go sixty years without getting cancer again?' Uncertainty and liminality in young women's accounts of living with a history of breast cancer. *Health*, 1363459316677628.
- Rogers, J. G. (2016). Managing VAD complications: Our growth industry, *Journal of the American College of Cardiology*, 67 (23), 2769-2771.
- Sandau, K. E., Hoglund, B. A., Weaver, C. E., Boisjolie, C., & Feldman, D. (2014). A conceptual definition of quality of life with a left ventricular assist device: results from a qualitative study. *Heart & Lung: The Journal of Acute and Critical Care*, 43(1), 32-40.
- Schutz, A. (1962) '*Collected Papers Vol 1, The Problem of Social Reality*', The Hague: Nijhoff.
- Shubin, S., Rapport, F., and Seagrove, A. (2015) 'Complex and dynamic times of being chronically ill: Beyond disease trajectories of patients with ulcerative colitis', *Social Science and Medicine*, 147, 105-112.
- Svenaesus, F. (2013) 'The relevance of Heidegger's philosophy of technology for biomedical ethics', *Theoretical Medicine and Bioethics*, 34 (1), 1-15.
- Svenaesus, F. (2011). 'Illness as unhomelike being-in-the-world: Heidegger and the phenomenology of medicine', *Medicine, Health Care and Philosophy*, 14, 333-343.

- Svenaesus, F. (2007) 'Phenomenology listens to Prozac-analysing the SSRI revolution, In. *Medical Technologies and the Life world*, (164-183).Eds. Lauritzen & Hydén Oxon: Routledge
- Svenaesus, F. (2000) 'The body uncanny- Further steps towards a phenomenology of illness', *Medicine, Health Care and Philosophy*, 3, 125-137.
- Takayama, H., Thomas, S. and Naka, Y. (2014) 'Transplant versus VAD: evolving and future perspectives', in Kyo, S (ed.), *Ventricular assist Devices in Advanced-Stage Heart Failure*, 97-111.
- Takeda, K., Takayama, H., Kaleson, B., Uriel, N., Colombo, P. C., Jorde, U. P., Yuzefpolskaya, M., Mancini, D.M. and Naka, Y. (2015) 'Outcome of cardiac transplantation in patients requiring prolonged continuous flow left ventricular assist device', *The Journal of Heart and Lung Transplantation*, 34 (1), 89-99.
- Taylor, B. and de Vocht, H. (2011) 'Interviewing separately or as couples? Considerations of authenticity of method', *Qualitative Health Research*, 21 (11), 1576-1587.
- Toombs, S. K. (1990). The temporality of illness: Four levels of experience. *Theoretical medicine and bioethics*, 11(3), 227-241.
- Trusson, Pilnick, and Roy (2016) 'A new normal?: Women's experiences of biographical disruption and liminality following treatment for early stage breast cancer', *Social Science and Medicine*, 151, 121-129.
- Turner, V. (1969) '*The ritual process*', Chicago: Aldine.
- Van Gennep, A. (1960). '*The Rites of Passage*', London: Routledge.
- Van Manen, M. (1984) "'Doing" phenomenological research and writing: An introduction', *Phenomenology and Pedagogy*, 2(1), pp. 26-39.

Westaby, S. (2015). NICE guidelines for acute heart failure: long on pills, short on pumps. *Br J Cardiol*, 22.

Tables

Table 1: Demographic characteristics of participants

Characteristic	Number of participants
Sex:	
Male	17
Female	3
Age:	
21-30	3
31-40	2
41-50	3
51-60	9
61-70	3
Ethnicity:	
White British	19
White Irish	1
Relationship Status:	
Married	14
Long term partnership	3
Single	2
Divorced	1
Time with VAD:	
Up to 12 months	5
1 year- 2 years	3
2 years- 3 years	6
3 years- 4 years	6

Partner present in interview:

Yes	11
No	9
