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Citation: Standing, Holly, Exley, Catherine, MacGowan, Guy and Rapley, Timothy (2018) 'We're like a gang, we stick together'?: Experiences of Ventricular Assist Device (VAD) communities. *European Journal of Cardiovascular Nursing*. ISSN 1474-5151 (In Press)

Published by: SAGE Publications

URL:

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‘We’re like a gang, we stick together’?: Experiences of Ventricular Assist Device (VAD) communities.

Word count: 4,567

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Abstract

Background: VADs are relatively new developments in the management of advanced heart failure. In the UK, VAD recipients comprise a unique group of less than 200 patients. This is the first paper to explore the experience of VAD communities, the extent to which communities are developed around the device, and how these influence the experience of living with the VAD.

Methods: Qualitative interviews were conducted with 20 VAD recipients (implanted as bridge to transplantation), 11 interviews also included the VAD recipients' partners. Interpretive phenomenology was employed as the theoretical basis guiding the analysis of the interviews.

Results: Four key themes emerged from the data: the existence of VAD communities; experiential knowledge and understanding; social comparisons; and the impacts of deaths within the VAD community. Many of the interviewees valued the VAD communities and the relationships they had formed with fellow recipients. Beneficial impacts of the VAD communities included offering recently implanted patients a realistic view of what to expect from life with a VAD, this could aid them in accepting and adapting to the changes imparted by the device. However, negative impacts of the VAD communities were also reported, in particular following deaths within the group which were a source of distress for many of the interviewees.

Conclusions: In general, the VAD communities appeared to be a beneficial source of support for the majority of interviewees. Consideration should be given to how these communities could be supported by clinicians.

Keywords: Ventricular Assist Devices; Bridge to Transplantation; Heart Failure; Patient Communities; United Kingdom

Introduction

Ventricular Assist Devices (VADs) are a form of mechanical circulatory support that are being used increasingly in the management of advanced heart failure. VADs augment, or fully take over, the pumping function of an individual's heart. There are two distinct types of VAD, transcutaneous and implantable;¹ this paper focuses specifically on implantable devices. VADs comprise of internal and external components; the external components include the controller and power source. The controller manages the flow of the pump, and communicates information about how the device is working, it has the capacity to produce textual alerts and alarms.² The VAD must be connected to a power source at all times either through specialised battery packs or mains electricity.

Implantation of the VAD involves major open heart surgery and a lengthy rehabilitation period, however the devices are designed to allow recipients to live at home.³ Day-to-day management of the device places substantial demands on the recipient⁴ including: maintaining power supply, cleaning and dressing the exit wound, and managing medications. The VAD also carries substantial risks including: bleeding and thrombosis, stroke, infection, and device malfunction.⁵ It has been suggested that the realities of living with the device may not be fully appreciated until they are personally experienced.⁶ The VAD can be a source of fear and anxiety^{7, 8}, it can lead recipients to experience a loss of independence⁷⁻¹⁰, and distress about the uncertainty of their situation.¹¹

In the US and Canada there are over 15,000 people living with VADs.¹² However, in the UK use of these devices is still in its infancy and VAD recipients form a rare patient group. Whilst there are over half a million people living with heart failure in the UK,¹³ there are less than 200 individuals currently on VAD support, and only around 600 devices have been implanted since 2004.¹⁴ These disparities are partly due to commissioning limitations in the

UK which only allow for the devices to be used as a bridge to transplantation (BTT) or for myocardial recovery.¹⁵ In the US, and much of mainland Europe, VADs are also used as a destination therapy (DT) which is an alternative to transplantation. DT accounts for up to 40% of individuals fitted with VADs in the US.¹⁶

Although, VAD recipients in the UK comprise a small group, they may encounter each other at several points: prior to implantation at meetings arranged by clinicians, during inpatient stays at the hospital, and at clinic appointments. All of these meeting points are potential starting points for new long-term relationships. However, there is currently limited research exploring the social networks of VAD recipients, and what does exist has focused almost solely on the impacts on caregivers.^{7, 17-22} To our understanding this is the first paper to explore the experience of communities developed around VADs, the extent to which these communities exist and their influence on the experience of living with the device.

Methods

Study design

This explorative qualitative study used interviews with patients who were living with, or had lived with a VAD. This paper focuses on one aspect of a study conducted as part of a PhD.²³ The study was conducted under the principles of the Declaration of Helsinki²⁴ and was approved by a NHS Research Ethics (Committee Reference: 12/NE/0218).

Sampling and recruitment

Clinician gatekeepers, specialist nurses and cardiologists, were used throughout the study to gain access to the study sample. Individuals were invited to participate in the study if they were living with, or had previously lived with a VAD. Clinician gatekeepers made the first approach about the study, they provided potential participants with the information sheet and sought consent for the researcher to make contact. Interested participants were then contacted

by the researcher to set up the interview. Figure 1 shows the recruitment procedure.

Participants were given the option of participating in the interview alone, having a partner present, or having someone participate in the study on their behalf to give a proxy account of their experience, however no one chose to take up this latter option.

Figure 1 here

A combination of purposive sampling²⁵ approaches were employed to ensure the study gave as full an account of the experience of living with a VAD as possible. The first round of data collection employed typical case sampling, clinicians were asked to identify individuals whom they considered to be 'typical' VAD recipients. As the study progressed, critical case sampling was used to identify individuals with specific characteristics that might test themes emerging from the data. For example, both those who were highly sociable within the VAD group, and those who sought to avoid contact with other VAD recipients were sampled. Data collection ceased when no new themes were emerging from the data. Ten VAD recipients approached by clinician gatekeepers declined to participate or withdrew before the interview was conducted. All respondents provided written informed consent for participation in the study.

Interviews were initiated with the question 'please tell me a bit about the process by which you came to receive a VAD?' This approach was intended to elicit a brief synopsis of the individual's medical history, allowing respondents the opportunity to give the history of their illness in their own words. An interview guide was developed for the interviews covering the following broad areas: experience leading up to and following implantation of the VAD; management of the physical components of the VAD; impact of the VAD on identity; and hopes and expectations for the future. All participants were asked about these broad areas. The interview guide was not a fixed document, it evolved over the course of the study in

response to themes emerging from the interviews. In line with the phenomenological approach the interviewer was open to topics and issues raised by individual participants.²⁶ For example, the idea of VAD communities emerged from the interviews themselves, this was not an issue that had been anticipated in advance, but was explored in greater depth through subsequent interviews.

Interviews were tape recorded and transcribed verbatim by the first author.

Qualitative analysis

Data analysis was informed by Heidegger's interpretive phenomenology.²⁷ The first step of data analysis involved familiarisation with the data through transcription of the interviews, and close reading. The second stage of analysis was to turn to each transcript individually, using line-by-line and highlighting approaches.²⁸ Transcripts were initially analysed line-by-line, this involved close reading whilst attributing a code to each segment of text, as the analysis went on there was a tendency to adopt a highlighting approach. Data collection and analysis occurred concurrently, emerging themes informed the interview guide for subsequent interviews and early transcripts were re-examined in light of subsequent interviews.

Trustworthiness of the data was ensured by several means including discussion of emerging themes within the study team, and detailed discussions of individual transcripts with a peer network of qualitative researchers. Whilst we did not engage in member checking²⁹ emerging themes were discussed in subsequent interviews. Findings were also fed back to key clinicians who acted as gatekeepers for the study. The purpose of this step was to establish whether the findings of the study were consistent with the clinicians' own experiences of working with this group. However, we acknowledge that the clinicians only

have access to the VAD recipients in the clinical setting, so their observations are limited to this environment.

Results

Overview

Twenty VAD recipients were interviewed, in eleven of the interviews a partner was also present and included in the interview. There did not appear to be a pattern in terms of who opted to have a partner present. Where the patient was married or in a long term relationship the partner was present in 10 of the 17 interviews. All of the respondents who were single participated in the interview alone. Participants of both genders included their partners in the interviews, and partners were included in interviews of participants across all of the age brackets. Interviews lasted between 40 to 105 minutes. All interviews were conducted face-to-face. The majority of interviewees were living with a HeartWare® II device, all were implanted at the same centre under the indication of BTT. Table 1 outlines demographic factors of the participants in further detail.

Table 1 here.

Four key themes emerged from the data: existence of VAD communities, experiential knowledge and understanding, social comparisons and impact of deaths within the patient group. Table 2 provides quotations for themes and subthemes. All names are pseudonyms.

Table 2 here

Existence of VAD communities

It was apparent that communities existed between many of the VAD recipients interviewed. Interviewees indicated they often utilised hospital appointments as an opportunity to socialise with other VAD recipients.

If you come to the clinic we all sit together or if there's any 'dos' [social events] all the VAD people stand together. (*Gary*)

For the majority of interviewees, the shared device was a link that drew them together with other recipients. Respondents were not necessarily all part of the same group, or community, but it was evident that most had formed relationships with other VAD recipients. In the majority of cases, these relationships were maintained outside of the hospital through text messages, telephone calls, and meet-ups.

Two of our closest friends at the moment are Connor and Helen (VAD recipient and wife) ... they sort of text or phone once a week, once every couple of weeks and we can just unload on them. (*Fred*)

VAD recipients and their partners had often developed relationships with other couples with whom they met up on a regular basis. However, younger VAD recipients, and those not in relationships also spoke of friendships they had with other recipients.

I went to the rehab groups for about a year or so just to get back in exercise and stuff like that I was the youngest one by about 40 years when I went, me and all the old dears it was great, I used to get a fuss made of us every time ... I met like 4 or 5 other people who had VADs and got really good mates with them. (*Grant*)

However, some of the interviewees expressed no desire to socialise with other recipients, indicating they saw no value in these contacts.

...if I'd broke my leg and somebody else broke their leg, does that mean we've got anything else other than that in common. (*Albert*)

Albert rejected the notion that the VAD was a sufficient basis for a sense of community; neither the VAD nor heart failure appeared integral to his sense of identity, and he did not wish to be defined through them.

Experiential knowledge and understanding

Although many of the interviewees had long histories of heart failure, the VAD was a new and potentially intimidating approach to managing their condition, of which they had little to no experience. Many had never heard of VADs prior to receiving one and the newness of the device to them could leave recipients feeling frightened and isolated. Contact with another VAD recipient could be an important transition point where they stopped feeling alone and began to feel part of a community.

I went from feeling as if I was on my own to then, well actually there's quite a few people (*Fran*)

Fellow VAD recipients were seen as a valued source of support. Contact with other VAD recipients appeared to be particularly beneficial around implantation, offering an insight into the realities of life with the device. Fellow VAD recipients offered the interviewees something that was missing from their other relationships, true insight and understanding of life with the device.

I found it a lot better talking to someone whose actually been there and done that, who's actually gone through the experience themselves. (*Jack*)

Exposure to fellow VAD recipients offering positive accounts of life with the device could alleviate fears, offering those who are living with uncertainty the hope of a more favourable future. However, some interviewees had also encountered those with negative accounts, which could have a potentially harmful impact.

There was a negative gentleman on the ward and you just wanted to say
'shut up, we don't want to hear it' (*Hannah, wife of Paul*)

The VAD communities also offered recipients the opportunity to share tips regarding the day-to-day management of the VAD.

Some people are very knowledgeable about them [VADs], very helpful, and
it's really practical stuff, you know, that they can be very helpful with.

(*James*)

Sharing advice on practical management of the device could spare recent VAD recipients some of the time-consuming and frustrating work of trying to fit the device into their day-to-day lives.

Adopting the role of 'experienced patient' by meeting prospective VAD recipients, could also have positive impacts for the individual.

It helps me as well ... it actually helps me to understand what I was going
through as well. (*Jack*)

Using personal experiences to reassure others and being positioned as someone who can (genuinely) help may allow recipients to develop new, and valued, identities that may replace those lost by the implantation of the device.

Social comparisons

Meeting other VAD recipients may also offer an opportunity for recipients to determine how well they are comparatively coping with the device. The majority of interviewees appeared to choose to compare themselves against VAD recipients who had experienced a number of problems with the device.

We [Fred and his wife] don't spend much time in hospital compared with other people on VADs. (*Fred*)

Reflecting that others' situations are worse may allow individuals to feel fortunate within a context, facilitating a positive view of their situation. These comparisons were not limited to health status, but could focus on other aspects of life with the VAD. For example, relative proximity to the hospital could alleviate concerns about the responsibility of managing the VAD, due to the security offered by having expert support close to hand.

Interestingly, the majority of interviewees positioned their experience as comparing favourably to other recipients.

Everybody I talked to they've all had infections, they've all had clots, water retention, [and] stuff like that. Some've had the VAD changed. (*Matt*)

Matt had actually experienced numerous complications with the VAD, including several driveline infections, and it is unlikely that every fellow recipient he encountered had fared worse. However, his focus on the negative experiences of others may be a stratagem for remaining positive about his own situation.

Not all of the respondents felt that comparing themselves to other VAD recipients was useful.

The way I look at it, everybody's different, nobody's the same. So you know, what happens to one patient probably, definitely wouldn't happen to another, you know there's not one patient the same. (*Ian*)

Rather than comparing himself to others, Ian stressed that everybody is different; comparisons are futile and will not provide any useful information about his own potential outcomes.

Impact of deaths within the VAD community

Death of a fellow VAD recipient appeared to have far-reaching impacts on many of those in the VAD community.

I've actually had, unfortunately, two people who've died, one of my friends Andy ... what I found hardest, because I'd met his family, I'd met his daughter and his two granddaughters and he'd waited so long for a transplant but then he died a couple of days later ... losing those two people was a bit hard to deal with. (*Jack*)

Death of a fellow VAD recipient appeared to have the greatest impact when there was a shared characteristic or other link. As Jack indicates above, Andy was not just a casual acquaintance there was a 'deeper' level of friendship.

A death amongst the VAD group often precipitated concerns of suffering the same fate.

It makes you start analysing yourself. You start analysing what's happened to them, what did they do compared to what you do? ... what kind of lifestyle did they have compared to what you do? (*Ned*)

Several of the interviewees reported trying to seek out as much information as possible about why other recipients had died. In particular, they wanted to ascertain whether the individual was at fault or whether there had been a problem with the device. A 'fault' with the individual appeared to be preferable as this affords the VAD recipients some control over their fate. Information gathered about the misfortune of others could be used to inform their own care regimens, however there is little they could do to safeguard themselves against a fault with the device.

Death of fellow VAD recipients could also result in feelings of frustration and anger towards the clinical team.

One of the lads I met on [the ward], just before Christmas ... he seemed alright, he was dead chatty and next minute ... she come in (his wife) and he didn't recognise her ... and then he died two days later ... I thought 'bloody hell, it can happen that quick' ... It just seems that a lot of people are now having more problems with it but obviously it's new and it's all to do with infection. (*Stephan*)

Witnessing such a dramatic shift in the condition of another could bring the fragility of their own condition, and mortality, into stark relief. Stephan's account also suggests a degree of irritation with the clinical team and an implication that he did not feel sufficiently prepared for the likelihood of experiencing such problems.

Discussion

This is the first paper to explore the experience of VAD communities, the extent to which they are developed around the device, and the influence on the experience of living with the device. Previous research has indicated that the opportunity to meet other VAD recipients and caregivers is an important event in the decision-making process,^{30, 31} and a high value is placed on the information gained from other recipients.⁴ The findings of this study indicate that whilst not all VAD recipients subscribe to the idea of a VAD community, the majority of interviewees find these relationships extremely beneficial. The value and significance of these relationships may change over time; they may be particularly valuable leading up to and immediately following implantation. Friendship with other recipients who are successfully living with the VAD appears to reduce feelings of isolation as well as allaying fears and fostering hope of a positive outcome. Similar impacts have been found amongst cancer patients³² as well as for online support groups.³³

VAD communities also appear to be a useful resource for learning how to cope with the device. Fellow VAD recipients are the only ones who possess experiential knowledge of life with the device. Experiential knowledge is defined as knowledge gleaned through personal experience with a phenomenon.³⁴ Research exploring the experience of living with a stigma has suggested that contact with others who share a stigma can be a source of practical and social support, through which the ‘tricks of the trade’ may be learnt.³⁵ Further, shared experiential knowledge can facilitate the development of a communal body of knowledge known as ‘experiential expertise’ that exceeds the boundaries of individual experience.³⁶ Indeed, interviewees described sharing tips for living with the device. The VAD communities appear to offer recipients an understanding of the experience of living with the device that is lacking from relationships with family and friends.

The VAD communities also allowed recipients to make social comparisons. Social comparisons occur between those who are similar or experiencing similar problems.³⁷ They are particularly prevalent in situations of fear and uncertainty,³⁷ where the preference is often for evaluation against less fortunate others³⁸ allowing for a more positive view of one’s own situation.³⁹ Many of the VAD recipients made downward comparisons to position themselves as more fortunate. However, as has been noted amongst patients with motor neuron disease,⁴⁰ the benefits of the VAD communities went beyond those which can be explained by social comparison theory to include exchange of practical advice and information, a sense of camaraderie and the potential to help others.

Potentially negative impacts of the VAD community were evident in the form of the distress experienced following a death within the group. Previous research suggests that death of a group member is one of the most difficult challenges faced by cancer support groups.³² Amongst hospice patients, it is suggested that awareness of the death of a resident leads others to reflect on their own future.⁴¹ Indeed, deaths appear to be a major event amongst

VAD recipients leading to grief at the loss of a friend as well as sparking fear of suffering the same fate. However, awareness of the death of fellow VAD patients may also act as a reminder of the vulnerability of their condition and a useful motivation to ensure they remain vigilant about the management of their device, in order to avoid experiencing similar outcomes themselves.

This paper is the first to discuss the impact of deaths within the VAD group. However, this is an under explored area in general, there is little previous literature exploring responses to deaths within patient communities. The majority of literature that does exist focuses on hospice patients, which has limited application to the VAD group. Deaths amongst hospice patients are often reported as more comforting than distressing.^{42 43} There is an assumption that hospice patients are nearing the end-of-life; death is expected, this not necessarily the case for VAD recipients. In UK context where VADs are primarily used as a BTT, rather than DT, witnessing others deteriorating, and dying, with the device is likely lead to upset and concerns over one's own future. However as the number of individuals fitted with VADs increases, deaths within this group will become increasingly common. As such, it is important to consider how to manage the impact on the wider VAD group.

The majority of interviewees appeared to have some degree of relationship with other VAD recipients. One of the influences on the degree of these relationships appeared to be geographical proximity to the implanting centre, and/or other VAD recipients. There was a group of recipients whom lived close to the implanting centre whom had become close friends whilst living with the device, and met up regularly. This group was relatively mixed in terms of the recipients ages, ranging from those in their 20s to late 50s, recipients sex, and relationship status. Other interviewees described close relationships with fellow recipients whom lived near-by. Given that the implanting centre from which we recruited covered a wide geographical area, it is likely that some individuals implanted with a VAD will not live

in close proximity to another recipient. This may have implications for the level of support that these patients require, it may be beneficial to monitor those who are live further away from the implanting centre, and other recipients, to ensure that they do not become isolated.

Limitations

Participants were sampled from a single VAD implanting centre, one of the largest in the UK; the experiences reported may have limited transferability outside of this context. Although the implanting centre where this study was conducted covered a wide geographical area, and attempts were made to sample a diverse range of participants, with different experiences' of living with the device, our participants were relatively homogenous, for example all were white British or Irish. Further research around VAD communities in the UK would benefit from a comparison between different implanting centres to test whether similar findings are evident amongst more diverse VAD populations. Further, given the differences in the commissioning of VADs between the UK and other countries, findings may not be transferable to countries where the devices are more commonly used.

Participants were sampled via clinician gatekeepers. Although efforts were made to ensure that a range of VAD recipients were included, gatekeepers had ultimate control over who was approached regarding participation meaning there may have been some patients' accounts which we do not have access to as clinicians decided not to approach them about participation in the study. Further research would benefit from using a range of recruitment methods, including those that would allow interested participants to approach the researcher without going through clinician gatekeepers.

As mentioned previously, at the implanting centre where this study was conducted there was a group of VAD recipients who had formed a particularly close friendship group. Several members of this group were interviewed, and it was evident they had discussed their

participation with each other. Their accounts, whilst useful, provide a very specific reflection on life with the device and are unlikely to be transferable to individuals outside of this group. Through purposive sampling approaches we sought to include those who had low engagement with other VAD recipients, however it is likely that those who were most isolated also chose not to participate in the study.

This paper does not discuss the role of internet support groups and forums. Only one respondent mentioned contributing to an American online forum for VAD recipients, although others reported watching YouTube videos of the implantation operation. It was decided that there was not sufficient data to discuss implications of online forums so this paper refrains from making inferences about this form of social exchange. A recent survey study has highlighted the potential of social media as a platform both for fostering virtual communities amongst VAD patients and disseminating evidence based practices for self-care.⁴⁴ Further research is required to explore the potential utility of these platforms.

In this paper we focus primarily on the community of VAD recipients themselves, however, it was apparent throughout the interviews that communities also existed around the partners/caregivers of the VAD recipients. Previous literature has highlighted the major impact of caregiving for VAD recipients,¹⁸ indicating a need for long term professional support.⁴⁵ It is likely that, as with the VAD recipients themselves, the development of communities around the VAD will be beneficial for relatives and caregivers. Future research should consider the development and impact of these networks.

Allowing partners to be present, and participate in the interviews, was an intentional decision by the research team when designing the study. We felt that this would help ensure that respondents felt comfortable in the research process. Partners were present in 11 of the interviews conducted. As mentioned in the methods section of the paper, there did not appear

to be a pattern in terms of which participants chose to include partners in the interview, however there may have been some practical factors influencing the decision. Although participants were given a choice regarding the location of the interview, all opted for the interviews to be conducted at the implanting centre. Several of the participants were in-patients at the hospital at the time of the interview, so options regarding location for the interview were limited, and the remainder of the interviewees opted to coincide the interview with their clinical appointments. For interviewees who were in-patients at the time of the interview, whether or not a partner was present may have been influenced by whether the interview coincided with visiting time on the ward.

Conclusion

Overall, contact with other VAD recipients appears to be beneficial to VAD recipients in helping them accept and learn to live with the device. Other VAD recipients were an important source of social support, offering experiential knowledge about life with the device and a level of understanding that may be missing from other social networks. Although, death of a VAD recipient could cause concerns within the group, this does not appear to outweigh the positive benefits of these communities but indicates a need for work to manage the impact of deaths within the patient group.

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