

**PARENTAL RESPONSIBILITY FOR PAEDIATRIC VENTRICULAR ASSIST DEVICES: VIEWS OF FAMILIES
ON THE ACCEPTABILITY OF HOSPITAL DISCHARGE**

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Abbreviations

VAD – Ventricular Assist Device

BHEx – Berlin Heart Excor

HVAD – Heartware

PICU – Paediatric Intensive Care Unit

HDU – High Dependency Unit

NG – Nasogastric

PEG – Percutaneous Endoscopic Gastrostomy

Abstract:**BACKGROUND:**

Paracorporeal paediatric Ventricular Assist Device (VAD) therapy requires hospital residency due to device and patient factors. Discharge home is potentially possible with a mobile driving unit. This study aimed to investigate family views on hospital discharge of a child on VAD.

METHODS:

Qualitative methodologies were adopted. We undertook 24 interviews of families who had a transplanted child previously on a VAD , and participant observations of two families who were current VAD patients residing in hospital.

RESULTS:

Families experienced overwhelming emotions as they spent time adjusting to the diagnosis, the need for transplant, family separation and financial concerns. Despite many parents being partially/fully trained on the VAD, the majority would be reluctant to be discharged, fearing emergencies, high burden of care needs and social isolation. Three families with a child on a Berlin Heart expressed willingness to reside in the hospital accommodation at least part-time, to facilitate private family time. One child on HeartWare was discharged home, with another going through the discharge process. Discharge was not acceptable to most families if this meant downgrading their child's transplant listing urgency status.

CONCLUSION:

Parents and children on VAD value independence and some private family time but not at the perceived expense of safety. Families preferred their child on VAD to remain resident in hospital even if mobility is improved with a mobile driving device. Parental education should acknowledge the high burden on families, risks of a remote setting and offer intermediate residency options. It cannot be assumed families want hospital discharge.

Introduction:

For the past 20 years, children requiring heart transplantation have had the opportunity to be bridged through the waiting period by mechanical circulatory support devices.(1) This approach has been successful in providing long-term support for patients who otherwise would have died.(2, 3) Infants, in particular, often require months of support due to the scarcity of organs for this age group.(1) For the majority of children on ventricular assist device (VAD), hospital residency is mandatory, due to device-specific factors such as battery life and weight.(4) Both hospitalisation and outpatient care on VAD have considerable impact on the child and family, although this has not been well studied internationally.(5, 6) The experience of home discharge on VAD in the paediatric population is limited.(7) As such, there is little data on young persons and their families' views on the acceptability of hospital discharge while on mechanical support.

The most common devices used in paediatric practice are the HeartWare (HVAD) and the Berlin Heart EXCOR (BHEX). The HVAD is a fully implantable pump which connects to an external controller and battery pack by a driveline exiting the skin. Children who are medically stable on HVAD can theoretically be discharged home with appropriate training and support.(8) The BHEX is a paracorporeal pump, connected to the 'Ikus' stationary driving unit, a wheeled machine weighing 100.6kg. The Ikus is designed to be constantly plugged into mains electricity as internal battery life is short. Carers are required to manually check the BHEX pump system for clots and functionality. Hospital residency is required.

Since the first BHEX implant in 1990,(9) the company records that more than 2200 paediatric patients have been supported. Despite worldwide experience, there is surprisingly little published data about families' views of this device and of discharge home on the HVAD.(5) As Berlin Heart advance towards market entry of a new mobile driving unit, it is important to ascertain the views of the patients and families who have experience of life on VAD. Considering the worrying psychological impact of living on a VAD seen in the adult population (10, 11), there is an urgency to

explore this. It is important to determine what the lived experience of children in hospital currently is and whether families¹ believe discharge home would be an improvement in quality of life and a beneficial therapeutic goal for this new technology. This is especially in light of the assumption that ambulatory care is the most desirable option.(7) The limited existing research in the paediatric population that discusses home discharge on mechanical devices (such as ventilation)(7), and VAD(5), highlight the social, psychological, physical and financial implications.(5, 7) Psychological morbidity such as depression, anxiety and depressive symptoms, are the most common mental health issues reported.(12) The VAD simultaneously helps the patient by supporting the management of their heart failure, while also causing long term hospitalisation and limited social interaction.(13)

In this qualitative study, we aimed to explore families' views on the acceptability of residence away from the critical care unit and the perceived impact of parental responsibility for this type of life-sustaining technology.

Patients and Methods:

Study design

Qualitative methods were adopted to allow for the exploration of the research topic(14), and gain in-depth data on families' views on home discharge on VAD. We have consulted the Standards for Reporting Qualitative Research to report this study(15). Considerable amounts of data can be produced from qualitative work, including field notes of observational research, and verbatim transcripts of recorded interviews(16). Semi-structured interviews and participant observations were adopted. All data collection was conducted by LC, who has no clinical background. Semi-structured interviews allow for participants to speak freely, and the interviewer to probe based on responses,

¹ For this study, we are using the term 'family' to discuss the whole family unit, not just the parents. Table 1 details which family members took part for each interview/participant observation.

but an interview schedule is used to allow for the interviewer to guide the direction of the conversation(17). This schedule can be loosely followed, and adaptations made based on emerging findings(17).

Undertaking participant observation, an approach that has its roots in ethnography, has been used as a means to understand and gain insight into relational interactions and immersion into the environment, over a period of time(18, 19). For this study, this approach was used to gain data about life on VAD and feelings about home discharge, with families who were currently living on VAD in the hospital setting; i.e. a deeper understanding of the patients' experience of their illness and the meanings ascribed to it(20). LC spent a lot of time with families, had lengthy discussions about life on VAD, was able to ask any questions and collected field notes on the content of these discussions over the period of five months.

Sampling, recruitment, data collection

For interviews, families were sent age appropriate information in advance of the child/young person's next clinic appointment. Children were able to actively participate in an interview if they were aged 8 or above. All families who had been on a VAD in the past 10 years were invited to participate. Exclusion criteria included families dealing with complicated grief; families involved in unresolved complaints or ongoing litigation and families who do not have a sound understanding of written and spoken English. Families were recruited and informed consent gained in the transplant clinic. Clinic was selected as transplant recipients have to attend a transplant clinic a minimum of four times per year, and patients could be travelling from anywhere in the UK. Thus, the clinic setting seemed the ideal place to capture patients. Participation did not in any way affect patients care, and interviews were conducted while families had lengthy waits. Interviews were conducted at that time, although families could request alternative settings, and this was accommodated on four

occasions². For eligible children, discussions were held with the family about whether to conduct interviews separately or together. Consideration was given to the age at which their child received the transplant; for example, if children were infants at the time of transplant, then interviews with parents were felt to be more appropriate. The age range was 1-21, with a male/female split of 13/12.

For the participant observations, a convenience sample of children on VAD in the critical care unit was recruited. Informed consent was gained prior to any observations carried out. Both families were observed several times per week, each time for 2-8 hours. During the study period, both patients received a transplant enabling observations to be made up to the time of discharge; one family were observed for two months, the other for five. Interviews were transcribed verbatim, and observation notes typed up directly after each observation.

Twenty-four interviews were undertaken with families of transplanted former VAD patients and participant observation with two current VAD families were carried out on in-patients who were living on VAD and their families. The total eligible number for participation was 52. Both HVAD and BHEX patients were included in this research, of whom all had varying experience residing in Paediatric Intensive Care Unit (PICU), High Dependence Unit (HDU) and the ward³. In total, 25 families participated in this research⁴ which represented the point where no new themes were emerging from the data(21).

Data analysis

An inductive thematic analysis(22) was conducted on the data by LC. This approach allows the generation of themes to be derived from the data, and not based on a pre-existing framework. The analytic process involves familiarisation with the data; transcribing the data, preliminary coding;

² Four interviews were not conducted in clinic. This was due to time restrictions of the family on that particular clinic day. In these cases, two home visits were arranged, a third over the phone and a fourth over FaceTime.

³ Observations were only carried out in HDU and the ward due to ethical considerations.

⁴ Twenty-four interviews, two observations. One observation family also took part in an interview. Their contribution has been counted as one.

refocusing analysis with the codes by sorting them into potential themes; searching for patterns or themes using these preliminary codes among all the transcripts; reviewing the themes; defining the themes; the final analysis and producing the end discussion(22). Interview transcripts and field notes were analysed using Nvivo software to support the process. A random sample of 40% of the transcripts were coded separately by ES and JR, to provide a qualitative equivalent of inter-rater reliability for the coding framework. This was conducted during the reviewing of the themes and enabled the decision on defining the themes. The themes with illustrative quotes are described below.

A favourable ethical opinion was received from the Newcastle and North Tyneside 1 Research Ethics Committee (17/NE/0267).

Results:

Table 1 provides some participant information. A total of 25 families took part; 24 interviews of families who were previously on a VAD and participant observations of two families currently residing in hospital on VAD, were undertaken. Children were invited to be active interview participants if they were aged 8 or above. We interviewed 11 of 17 eligible children⁵. Four children were interviewed without their parents; seven interviews were with children and their parent(s); and fourteen only involved the parents. For the participant observations, children and their parents were both involved. The sample included one family who had experience of home discharge on VAD, and one family who were in advanced stages of the discharge process. This paper focuses on two main themes; acceptability of discharge from hospital and responsibility for the VAD. While 17 of the 25 families were BHEx patients, with eight HVAD, the views between BHEx and HVAD were

⁵ For those eligible by age but not interviewed, the reason was mainly due to the child suffering some form of learning disability.

remarkably similar despite the mobility the HVAD already offers compared the BHEX. As such, views are presented together. Our data revealed no differences between family members.

Acceptability of discharge from hospital

In general, families expressed deep concern about the notion of leaving hospital if their child was on BHEX or HVAD. Even living in hospital accommodation⁶, despite being slightly more of a consideration, was accompanied by trepidation, which for many families outweighed the perceived benefits of discharge.

I can definitely see the benefits, but it's whether we could cope with all the demands of the nursing requirements. (INT FAM 1)

No, she (mum) would just take us straight to hospital, because she wouldn't manage. (INT FAM 3, CHILD)

I'm not carrying that around the streets, it's embarrassing. (INT FAM 10 CHILD)

If something went wrong in the middle of the night, what would you do then? (INT FAM 11)

While families wished it was not necessary to be in hospital, this was not remedied by simply discharging on VAD as it brought with it many other problems. Current practice in the UK is that children who are stable and low risk (managing as outpatients), are moved from the urgent to the routine transplant list. The majority of families reported they would refuse discharge whenever possible on this basis alone. Participating children themselves also reported hesitation about being away from the hospital premises, or if this altered their position on the urgent transplant list.

I'd stay... if it swapped her place on the list, there is nothing I would have traded for that, because time is very limited. (INT FAM 17)

⁶ The parent accommodation is a self-contained accommodation block on the hospital site.

Because they said I'd have been on the transplant thing longer and it would have been I'd have had to wait longer... I didn't want that. (INT FAM 2 CHILD)

Probably hospital... Because so much stuff can go wrong. The machine not working (INT FAM 15, CHILD)

When it's your child, it's always going to be urgent. (INT FAM 18)

Three families whose child was on a BHEX, felt they may have accepted an option of taking their child to the hospital accommodation for some quality time together. A family meal, or watching a film were some of the 'normal' things these families discussed doing, then returning their child to the ward.

if it was a bit more portable. It would have been nicer to maybe have family time that was private... it would have been nice just to like be able to prepare a meal, sit down together and eat that rather than having to eat a packet sandwich together or watch a movie together... even just a few hours out in the day might be nice. (INT FAM 22)

Maybe for a few hours and then bring her back... I don't think I would have felt comfortable to have her there all on my own for days and nights. (INT FAM 6)

Our sample included one family that were discharged on HVAD, and another who were in the process of home discharge. The discharged family felt their location to the hospital, and wanting to be out of the hospital setting meant discharge was acceptable to them. However, her own mental health was impacted by this.

I had post-traumatic stress. I had gone from an independent woman overnight, to this nervous wreck... I was hyperventilating. I was having panic attacks. I was having flashbacks. But I knew I couldn't go on like that, because I had him to think of... A person can only take so much. The {Hospital} obviously became my family, because the staff, parents, patients... I was here, and I was content. Obviously, he was in the right place. But when I got home, I just

felt as if I had gone from everything to nothing. It's like back to reality, but it was in a bad way. (INT FAM 9)

Living far away from the transplant centre would have led to a different decision, and the family report re-admission on deterioration of her child's condition. For the family being prepared for discharge, this acceptability centred on professional presence to support the VAD, allowing parents to do the 'normal' parent things. This family were hoping for explantation due to recovery, rather than transplant, which also influenced their decision making. Their planned discharge was on the basis of 24 hour support being present. A donor became available before discharge occurred, which the family accepted.

I did say to the ward that I didn't feel comfortable (being discharged). But we had carers that came in and helped us and when we went on a home visit we weren't on our own; we had carers that came with us and they were trained on the HeartWare because he needed 24 hour supervision. (INT FAM 4)

Discharge was seen as an opportunity to do 'normal' family things. For the majority of families, however, this did not outweigh the risks of a catastrophic event. For the one family who were discharged home, the doing of 'normal' things was not reported, only the care demands and heightened fear. Most of the families described witnessing something happening to their child, or a child in their vicinity, suddenly and immediate care being provided, for example, a stroke, or a cardiac arrest. Of those able to report an answer, children also took comfort from the doctors and nurses being on hand should anything happen. Families viewed hospital discharge with VAD as having risk. Requiring health professionals who can respond immediately to emergencies was a key concern, as well as the distance to get to a safe place with personnel, equipment and space.

... he was heavy clotting and the little ones usually are, and so we just wouldn't have been comfortable without being able to get, you know, if a surgery was needed or something to remove a clot, without having that, you know, right there. (INT FAM 7)

They react so quickly that the thought of being even within the grounds of the hospital, from there, right to the other- is it five minutes to get there, that just might be too late... as much as we don't want our child to be in hospital, if they have to be they have to be and that's just it. (INT FAM 8)

Because you know how quick they can deteriorate, like, it can take two seconds for them to just – even if the machine stopped working and if the heart couldn't cope. Especially when she had the stroke. She was just playing, and her left arm just went. She couldn't, like, move it or she couldn't pick anything up... they took her for a CT scan straightaway and then that showed she had something on her brain. (INT FAM 23)

Concerns about sleep deprivation were also revealed, as some parents reported they would want to remain awake to check their child was ok.

Personally, I wouldn't have slept, and it would've got to the point where I literally just fell asleep (INT FAM 20)

You need your rest when you're here (INT FAM 23)

Those with additional children raised concerns about their ability to be an adequate parent to their other children as they could not leave their child on VAD alone. OBS FAM 2 were fully trained but discussed refusing discharge with their stable child on the HVAD. Concerns included: change of listing status from urgent to routine transplant list; and the effect on the child's quality of life at home due to the constant need for a parental presence. The stigma of a nasogastric (NG) tube was also concerning. These things combined meant that going home would have the potential to reduce the quality of life of the child.

Initially we were pushing to go home as we didn't see the point in being here. We were put off by the NG tube and people staring at him, and the fact that we would need to treat him

like a baby. Then we found out that he would come off the urgent transplant list and could be on the VAD for years so we put the brakes on going home. (OBS FAM 2)

Regarding the usefulness of having a new portable driving unit as an alternative to the Ikus, families wholeheartedly welcomed the improved independence it would bring and the possibility to have more private family time. Being able to transport their child to different areas of the hospital more easily, such as the play room, without relying on several members of staff to support the move was viewed by parents as being an invaluable benefit to the families.

She doesn't get to go nowhere near as much as I would like as it takes so many people to move her. (OBS FAM 1)

Responsibility for the VAD

Discharge from hospital transfers the caring responsibility of the child, including the VAD and their medications, to their parents (or other legal guardians). Current practice at the study hospital is to increasingly involve parents in the care of their child as confidence grows within the hospital environment; different parents have varying degrees of involvement based on what they feel comfortable or confident doing. Parents stressed that the challenge of this responsibility would be multiplied if they are expected to move outside of the hospital setting. Both observation families for example, demonstrated their technical capability with the VAD, yet neither wanted to leave the hospital premises. The security of being in the hospital contributed to their confidence with the VAD, where the ultimate responsibility was not with the parents but with hospital staff.

This study revealed a range of parental views to caring duties. Some parents feel the emotional turmoil is enough to deal with alone without taking on caring responsibilities, especially as looking after the BHEX would additionally involve checking for clots and more complex dressing changes. Other parents wanted to have some involvement to regain some element of control over the decisions being made regarding their child.

It's doing too big a job. You know I'll quite happily change over a bag of fluids or stop her fluids and shout and say 'that's her fluids finished'... I did all her PEG, her dressings on her Hickman line, but the Berlin Heart is doing too much for me to mess with it. No, just no. (INT FAM 15)

I can't imagine being in hospital accommodation with a child on a Berlin Heart, I can't get my head round that really. (INT FAM 8)

Some parents also recalled practical issues; for example, one parent could not change her child's nappy while holding up both pumps. Interestingly, engaging with training and having the confidence and ability to undertake procedures and caring tasks did not automatically equate to willingness to discharge and take sole responsibility for the child. For example, OBS FAM1 (mother) was very confident in doing all her child's basic nursing care including passing an NG tube, however, she felt very strongly that her child on BHEX should be looked after by experienced nurses one-to-one in the PICU rather than at any lower dependency level.

I couldn't have cared for him by myself, him being on those VADs... I couldn't care for him, on a personal level... I couldn't change his nappy. (INT FAM 15)

My daughter is on a Berlin Heart, she should be in PICU. (OBS FAM 1)

It would be just too much hassle. I'd be too scared to... the stuff that we would have had to take with it as well, with her having a trachy. It would have been too much for us. (INT FAM 23)

Additional stressors also have to be factored into any potential decisions for discharge: two families remembered their child experiencing withdrawal from sedation drugs and the management of problems like this was an additional reason for wanting to remain in the hospital.

One of the worst bits was coming off the... would it have been morphine? It was like cold turkey, and that was terrible, seeing the withdrawal programme they gave her. (INT FAM 8)

I think I could have done it, if she hadn't struggled so much with withdrawing. Because she had been on morphine for so long, they had to put her through withdrawal on Methadone, and Diazepam. That bit I really struggled with, much more than the Berlin Heart or anything.
(INT FAM 17)

Two families expressed concerns about 'being forgotten about' if they were not physically present in the hospital.

You always have that gut feeling that if you get sent home they kind of forget about you.
(INT FAM 10)

I always think 'out of sight out of mind'. I know that's probably not the case, but if they're looking at you all the time... (INT FAM 12)

For some families, increased responsibility for the VAD came alongside heightened fear. Fear was an ever present concern throughout all discussions as their child is already experiencing a drastic treatment option, which is keeping them alive. This invasive and highly risky treatment option is life changing and incredibly scary in itself for families, without the added stressor of being responsible for it outside of the hospital premises with no medical professionals present. For many families, the perceived benefits of discharge and responsibility for the VAD, was not enough to mitigate against this fear.

I would have been too afraid to because of the risk factor. Because any risk is a risk, even if it's low risk... Why would you do that to your child, is my opinion. The fact that you are even in hospital needing something so drastic. (INT FAM 5)

Yes, have the nurses there, have the doctors there, just make sure we were close by ... if we had not been in hospital we actually would have been probably more nervous. (INT FAM 7)

If something was going wrong with it, if you're in that hospital, you get treatment ASAP. If you were at home... (INT FAM 12)

Hospital Accommodation is there but it's still... I think it's still too far away, to be honest... it's still a five/ten-minute walk. (INT FAM 15)

Ultimately, families want to take home a surviving child. Therefore, safety is paramount to families and more important than hospital discharge. Overall, families were reluctant to reside in hospital accommodation or home with a child on paracorporeal VAD, despite private family time being missed and valued.

Discussion:

This study explored families' views on hospital discharge and responsibility for their child on VAD. Overall, the participants were not accepting of discharge, and unwilling to take sole responsibility for their child's VAD. Parents were concerned about listing status, safety and responsibility for the device. This fear increased with distance from the critical care area, even among parents who had received VAD training and had a child on HVAD. Our hope is that accumulation of experience engenders confidence in safety nets and support mechanisms and would be an interesting area for further study. The period waiting for transplant was referred to in the pre-HeartWare era as "supreme torture" and "living with a time bomb".(23-25) As yet, there is minimal data on what psychological and mental health impact modern VAD therapy has upon the children, parents and siblings. While VAD has enabled the survival of children through bridging to transplant, mortality and complications exist due to sepsis, thrombosis and bleeding.(26, 27) Mortality and morbidity data for the BHEx exist for a population largely resident in critical care units and there are no published data comparing health outcomes of VAD children looked after solely by their parents, which is needed to properly compare the two options.(27)

This research supports previous findings that family members have to face challenges related to the uncertainty of waiting, changes in the child's physical function, the needs of the ill child, financial

burdens, and the disruption to daily routines, while at the same time trying to maintain some semblance of a normal life.(11, 23) In some instances, families have to relocate to be close to the transplant centre, with consequences in terms of the support they receive, changes in roles and responsibilities and needing to put their lives on hold.(28) Families in this study either lived separately or relocated temporarily, supporting previous findings of huge upheavals. This study suggested family coping may sometimes be worsened by discharge, despite, on the surface, this seeming like an obvious solution.

It is known that caregivers of adult VAD patients experience limited life experience; feeling themselves 'tied' to the patient and may become isolated as well as suffering stress from the uncertainty.(29) Casida interviewed carers of adult VAD patients discharged home and found that emotional distress could be followed by determination and ultimately optimism.(30) In another study, caregivers reported substantial depression and anxiety pre-implant that did not improve over time.(11) Families of children on ventilation residing at home also report isolation and psychological, social, physical and financial consequences.(7) Caregiver stress was a real concern of the study families; they felt this situation would pose an additional risk to the child. Parental confidence with skills and procedures did not change this perception. The difficulty of being both a parent and a carer was highlighted in this study, and the strain of being a family member and carer(31), as well as life-threatening diseases potentially causing post-traumatic stress disorder, is well recognised.(32, 33) The one family who was discharged home reported post-traumatic stress and panic-attacks on discharge on HVAD, supporting previous findings of caregiver stress for those discharged on medical equipment.

Family functioning in the period leading up to transplant has been found to influence the child's post-transplant psychological function more significantly than their medical severity.(34) Facilitating important family time while a child is receiving VAD support is therefore an important goal for long term care.(34, 35) One aim of discharge is to enable the family to function better as a unit, but in

the current study parents questioned whether this will necessarily be the case, even for those with an intra-corporeal device. Being tied to parents, the confines of the hospital accommodation or home, and lack of sleep for parents, were some of the reported concerns. Research has found siblings of the sick child to be resentful of the extra attention received by the child, and the additional needs of the sick child having a negative impact on the family unit, such as isolation though not being able to do 'normal' things.(7) That being said, enhancing privacy and independence would be welcomed, with device mobility highly desirable to enable this. While children have now had sustained periods at home, with some returning to school, this requires both a medical and social support structure to be in place.(8) Differing healthcare systems may also influence family views on hospital discharge with a child on VAD. This study was conducted at one UK National Health Service Centre. Unfortunately, only one discharged patient was recruited to the study due to only a small number of patients available to sample from, and the recruitment strategy taking place in the transplant clinic, where explanted patients do not attend.

This study makes no claims to generalisability of the views of all VAD patients. We provide a valuable insight into the views of 25 families, two of which were current VAD patients. We also acknowledge that 23 of the 25 families were discussing their views retrospectively after a successful transplant; had we asked their views while currently living on VAD, or spoken to families whose child did not survive, then some different views may have been elicited. Research has concluded the impossibility of families being truly prepared for the reality of VAD implantation(6, 36) as well as the burden on caregivers,(8) so this insight running counter to the assumption that 'home is best' is important to future discussions about optimal care for children and young people on VAD.

We cannot assume that families always want discharge home, even if it is believed clinically it would be the best option. It also cannot be assumed that what clinicians see as an acceptable burden of care and responsibility is achievable for families and ultimately, is 'safe' for the child. Going forward, we would propose that each of the issues raised by families in this study need to be carefully

considered, discussed and addressed, in order to align parental and clinician expectations and goals. From this, we propose the co-design of a discharge programme bringing together children, families, clinicians, the community multi-disciplinary team, researchers, and stakeholders, should this be the direction families want to go in. Families not being discharged also need to be supported to have the degree of independence appropriate to their circumstances. Evidence of learning from discharging paediatric VAD patients in a US insurance based system have been published (37, 38), but it is essential to continue to add to this. It is important to consider family views on such programmes and differing healthcare systems, especially as evidence shows responsibility of a VAD device and living with a machine may cause depressive symptoms.(12) It may be worthwhile exploring whether different perceptions exist within families.

Suggestions for clinical practice

- Hospital care teams should make efforts to provide each family with private time alone, if at all possible.
- Mobile para-corporeal technology is expected to improve the freedom and quality of life of children on VAD but discharge home should not be an expected outcome until this is of proven safety and benefit.
- Families struggle with the emotional and practical challenges of the bridging period and experiences of helpful interventions need to be shared between hospital care teams.
- In this single-centre study, families showed a lack of understanding for the complexities of transplant listing status and criteria in general, with a tendency to oversimplification.
- Transplant teams should ensure that a change in listing status does not become a barrier to discharge home, if this is desired and felt to benefit the child.
- Goal setting and discharge planning should deal with the specific concerns of families and should be individualised and achievable.

- Development of a discharge programme, co-designed with all relevant parties. Working with families around discharge will ensure their views and concerns are considered and addressed.

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Disclosure

The authors declare no conflict of interest.

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