Talking with caregivers of children living in the community with ventricular assist devices

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Abstract
A VAD is a mechanical pump used to support the functioning of a failing heart. As a pediatric therapy, a VAD is used as a temporary solution for poor heart function, a bridge to transplantation or recovery, or a destination therapy. The goal of this qualitative study was to explore the perspectives of family and professional caregivers of children who are supported by VADs in outpatient settings. Semi-structured interviews were conducted with 22 caregivers of school-aged children discharged home on VAD support. Interviews were transcribed, and data were analyzed using qualitative content analysis. Caregivers identified issues facing children on VAD support in the contexts of home, school, and other childhood places including being physically connected to a device; experiencing changes; living a medical life; negotiating restrictions; cost of care; family, kinship, and community; and, present and future living. While a child with a VAD may have much in common with other medically complex children, the technological complications and risks of living with a VAD are uniquely identified by caregivers as an issue, especially when considering the way that children with a VAD are connected to their device—implanted yet exterior, mobile yet restricted, and autonomous yet dependent.

Keywords
congenital heart disease, heart failure, qualitative research, technology dependency

1 | INTRODUCTION

A VAD is a mechanical pump that may be used as a temporary solution for poor cardiac function, a bridge to transplantation or recovery, or a destination therapy for non-transplant candidates.1-4 A variety of VAD systems exist such that a VAD may be placed internal or paracorporeal; pneumatically or electrically driven; and provide pulsatile or continuous blood flow.4

VADs are proving to be an increasingly successful therapy for pediatric heart failure.1,5-8 Patients are being supported for greater lengths of time, and for those on continuous-flow pumps, in outpatient rather than hospital settings.9 As such, some children with these devices are living at home, attending school, and able to perform activities of daily living.

The use of VADs, however, is not without considerable risks, such as bleeding, thromboembolism, infection, hemolysis, and multi-organ failure.10,11 More so, VAD implantation in young and adolescent children is recognized to be associated with psychosocial and quality-of-life-related effects.12,13 Still, it is not clear from the available literature what particular challenges pediatric patients with VADs face because overall, the experience of sending children home on these devices has been limited.14 Even experienced healthcare professionals who work
in VAD Programs may lack understanding of the needs of children who require VADs and the problems of families who support them.\textsuperscript{15}

The aim of this qualitative study was to explore the perspectives of caregivers of school-aged children who had been implanted and discharged home from hospital with a VAD.

## 2 | MATERIAL AND METHODS

### 2.1 | Study design

In order to understand how VADs affect the lives of school-aged children, a media ecology framework was used to guide the study. Media refers to the effects of a technology.\textsuperscript{16,17} Ecology refers to the study of environments: their structures, contents, and impacts on individuals.\textsuperscript{18} From a media ecological perspective, the environments (home, school, hospital, etc., including supporting technologies and background infrastructure) in which a child spends time have important implications for his or her development. Caregivers were conceptualized broadly as adults who meaningfully encounter children with VADs in caregiving roles. They were recognized to have special knowledge pertaining to VAD children at home, in school, and/or other places. The study received independent review and approval from the University of Alberta Research Ethics Board. Informed consent was obtained from all participants.

### 2.2 | Sampling and recruitment

Participants were recruited from the Stollery Children’s Hospital VAD Program, the major pediatric VAD referral center for Western Canada. Care has been provided for a total of 9 pediatric outpatients since its inception in 2005 (internal audit). All school-aged VAD pediatric patients who have been discharged home have been implanted with continuous-flow devices: HeartWare HVAD\textsuperscript{\textregistered} or HeartMate II\textsuperscript{\textregistered} (Thoratec Corporation, Pleasanton, MA, USA).

Parents of school-aged VAD children (age 7-18 years) were purposively approached after verifying with the VAD Program that there was no current significant psychosocial distress. Additional caregivers (physicians, nurses, teachers, dietitians, physiotherapists, child life specialists, and administrative staff) were identified by snowball sampling: recruited caregivers were asked to identify other caregivers who were believed likely to have important insights into the lives of school-aged children living with VADs.

### 2.3 | Data collection

Qualitative data were generated using one-on-one interviews to elicit issues perceived to impact children and adolescents living with a VAD. Open-ended questions were structured to facilitate communication and to create a sympathetic, confidential, and respectful environment while simultaneously capturing the various ecological domains of the media ecology framework (see Table 1). The interviewer had no prior contact with the families and was not associated with the VAD Program. Interviews were conducted by phone at a time convenient for the caregivers from January 2015 to October 2016. Discussions were audio-recorded and transcribed verbatim with identifying features removed.

### 2.4 | Data analysis

Interview material was analyzed using content analysis, an empirically grounded method suited for exploring the meanings (contents) of qualitative data.\textsuperscript{19} The aim of employing this methodology was to articulate explicit and replicable meanings and to derive valid inferential insights from text or other source data.\textsuperscript{20}

Data were managed by a qualitative computer package NVivo (QSR International). Transcripts were independently read and coded by two of the authors after a prolonged interpretive engagement with the transcribed text. Saturation of themes was reached.\textsuperscript{21} Discussion and comparison of coding informed the final composition of the manuscript. No weight was given to the frequency of particular identified themes as the method of recruitment was in part based on convenience. Included anonymized quotes from the transcriptions provide supportive evidence for the validity of themes and to help convey contextual meanings to the reader of the findings of the study.

### Table 1 | Key interview questions

| Questions directed to all caregivers: |
|-------------------------------------|
| What unique challenges do you think children with VADs face? |
| What are some positive ways that a VAD may affect a child’s wellbeing or development? |
| What are some negative ways that a VAD may affect a child’s wellbeing or development? |
| What are some strategies that may be used by caregivers to support children with VADs? |
| What do you feel should be design priorities for new VAD or related technologies? |
| What are some negative effects of VADs for children? |
| What are some positive effects of VADs for children? |

| Questions only for parent caregivers: |
|-------------------------------------|
| What is life like for your child with a VAD? Specifically, how do you see the VAD impacting their life at home, at school, or in the hospital? |
| What do you worry about for your child with a VAD? |
| How does your child respond to the VAD? How does it make your child happy or sad? How does it make your child anxious or calm? |
| How do you see others responding to your child with a VAD? What positive responses have you witnessed? Have you witnessed any negative responses? |

| Questions only for professional caregivers: |
|-------------------------------------------|
| How do you feel the children you care for with VADs generally fare? |
| What challenges do you witness children supported by VADs face in your place of work? |
| What challenges do you think children supported by VADs encounter at home or anywhere outside of your place of work? |
| What makes a VAD good or bad? |
| How do children respond to the VAD? Does this response change over time? |

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3 | RESULTS

Table 2 describes participant characteristics. A total of 9 family interviews (representing 6 children with VADs) and 13 professional interviews were conducted. Interviews lasted for approximately 30-60 minutes. Table 3 provides a listing of themes and representative quotes to illustrate each, separating family and professional viewpoints. The considerable overlap, yet at times divergence in expressed themes, is discussed below.

3.1 | Being physically connected to a device

Both family and professional caregivers discussed how the simple fact of being connected to a device may be a significant issue for a child. As the device was incompletely implanted, the driveline, controller, and power supply need to be carried: a potential disruption to the physical and psychosocial life of a child. Families and professionals discussed how living with the device necessitates device routines, such as changing batteries and plugging in at night. Some routines were reported as more cumbersome such as cleaning the driveline site or completing dressing changes. Over time, or at the very least at times, it was discussed by most families and professionals how the VAD could become a habitual presence in a child's life.

Caregivers variably reported children feeling the device. Relative to professionals, families tended to discuss more of the sensations of the device itself ranging from its vibrations and noises, to the tactility of scars and bumps, and of course to the pain that could be provoked by a pull on the driveline itself. Both families and professionals reported less differentiated symptoms such as malaise or nausea although, for the most part, the device was described as restorative of energy and drive. Families discussed how children variably responded to these experiences with emotions such as anxiety and worry; frustration and rebellion; or simply, indifference. Overall, it seemed that most children found ways to cope with the device ranging from distraction strategies, talking with parents, pain or psychiatric medications, or seeking support from counseling experts.

### TABLE 2 Participant caregiver roles (n = 22)

| Family members      |      |
|---------------------|------|
| Mothers             | 5    |
| Fathers             | 3    |
| Other               |      |
| Aunt                | 1    |
| Professional caregivers |    |
| Physicians          | 5    |
| Nurses              | 2    |
| Teachers or school staff | 3    |
| Other               |      |
| Child life specialist | 1    |
| Dietician           | 1    |
| Physiotherapist     | 1    |

Accessories that permit carrying the VAD are not necessarily pediatric in size such that children relied on custom or even homemade backpacks, purses, or other carry bags to allow the VAD to be securely worn and to attenuate its physical presence. Even with such accessories, the driveline of the device was always reported to be exposed to some degree, vulnerable to pulls, tugs, or harm such that deficiencies in the design of the VAD were described by both families and professionals.

3.2 | Experiencing changes

Families and professionals described living with a VAD as a significant life change. Most professionals, and a few parents, recognized the baseline health of a child impacted the experience of change. For example, for a child who had lived with long-standing compromised cardiac output, the VAD was celebrated as a positive change giving vigor and vitality. Conversely, a child who needed a VAD following a sudden event required more support in accepting the necessity of living with a VAD.

Transitioning away from the hospital with the VAD, while often experienced as stressful, was ultimately seen as a positive change by families and professionals. Many described the first weeks to month following implantation as difficult because both child and family needed time to become accustomed to the device routines.

Family and professional caregivers mentioned day-to-day worries regarding the possibility of unexpected changes and having to deal with emergencies such as driveline site infections, brain injuries secondary to clots or bleeds, device failures, or even death. It was also discussed how different children have different understandings and awareness of such possibilities, yet caregivers realized that such occurrences could be life-changing. The possibility of readmission was reported as a significant source of stress for children and families. Caregivers described how differently particular children fare with the device depending on individual, family, and other factors.

3.3 | Living a medical life

Families emphasized the value of close connections with the VAD clinic and other health professionals, particularly in the initial weeks to months of transitioning home. These connections served as significant sources of support for families and their children. Being constantly in touch with the healthcare team meant more than attending clinic visits and responding to abnormal bloodwork. Close connection also meant frequent phone calls and other support that the clinic (locally or remotely) provided. Families and professionals described living a medical life as easily disruptive of ordinary life due to clinical visits, medical tests, dietary restrictions, medication administration, and other necessary activities to ensure appropriate functioning of the VAD.

Families who lived farther away from the VAD Program tended to experience a lack of expertise in hospital emergency rooms and physician's offices, even if they were residing in or near an urban center with pediatric services. Having to relocate or being unable to relocate near to the VAD Program was recognized as an important issue by families and professionals.
3.4 Negotiating restrictions

Protecting the device was reported as an issue for children invariably by families and professionals. Accessories that allow the VAD to be safely worn were described as often inadequate. The driveline was frequently mentioned as the vulnerable part that could be damaged, lead to complications, or simply inflict physical pain on the child if not properly secured. The driveline site was considered

**TABLE 3** Qualitative data themes and representative quotations, organized by domains

| Theme | Representative illustrative quotations |
|-------|----------------------------------------|
| **Being physically connected to a device** | |
| The physical device | “It’s really hard for him to sleep, he couldn’t really turn on the one side very well. If he crawled around on the floor to play he had the backpack and it would flip kind of over on his head, and it made it hard for him to move around” | “Living with a machine attached to them, it becomes a severe alteration of their lifestyle” |
| | | “In a perfect world it would be fully implantable” |
| Batteries, plugs, and power routines | “I mean with today’s technology you’d think that the batteries would be a little bit smaller. And they would be a lot lighter, and they would last a lot longer. We’re only getting four or five hours out of the batteries” | “You always got to have two batteries with you, you always got to be near a power source, and you have to make a backup plan” |
| Feeling the VAD | “He didn’t feel great all the time, he felt kind of yucky...he had a hard time sleeping because when you lay on a pillow with it, the vibration from the actual VAD comes up, and your pillow is like an amplifier and a speaker, and you can hear the pump all the time” | “There’s days that for whatever the reason, they don’t feel that well...days that they’re vomiting for no apparent reason, headaches for no apparent reasons” |
| Making it work | “We got a couple different backpacks and we’ve tried a few designs and we’re still working on some. I’m working right now on one to try to put a little bit of a cover because the controller gets quite hot” | “It was miraculous to see her running and playing with other children. And she didn’t care, when she could wear it in the backpack...I can still picture her running with that backpack, bouncing along behind her” |
| Routine presence | “She’s very well adjusted, actually. So we really don’t, we don’t spend a lot of time discussing it anymore, it’s just become part of our life” | “They become habituated to it...one kid I think even kind of missed it when it was gone” |

**Experiencing changes**

| Promised positive changes | “With the VAD, she started building muscles and eating, basically meals...it’s a very big deal to not have any tube in her nose and start eating on her own” | “It’s life saving. Most of these children in the past before VADs were really implemented would have died from their heart failure” |
| | “The biggest thing about having the VAD is we were able to go home and not have to be in a hospital” | “She was so thrilled to be able to run and jump and, you know, to have that physical strength to move around” |
| Change as relative | “At the time, although her doctors, and if you looked at her medical numbers, her cath reports, they all looked like she was very sick, but she didn’t feel sick...so she really didn’t feel that it really benefited her much, she did not feel that it had improved her life in anyway” | “For a kid who’s born with a heart defect or who’s had a long-term heart issue and has been so sick...they see it as life-saving” |

**Disabilities, impairments, deficits, and unexpected changes**

| “We actually don’t really know what the cause of the stroke was: risks on the ECMO machine, risks of putting the VAD in. There were a number of factors that could have contributed...the positive effects of the VAD were kind of obscured by it” | “Potential complications, if they have an infection that they might have to go on antibiotics, so that may mean if they were out at home, they might have to come back into the hospital. Sometimes even just something as simple as diarrhea means they have to come back” |

**Everyone’s different**

| “[Child’s name] is a really unique kid. We actually keep waiting for some psychological effects of it. He wasn’t afraid of the VAD. I would think a lot of kids would be afraid of the device itself. But he really wasn’t” | “[Child’s name] has been in and out of hospital quite frequently, over the course of her years with the VAD. So I think that’s definitely put a toll on her in terms of developing friendships with children her age, attending school regularly. [Another child] has been doing really well and she’s at her regular school, so that’s been great to see” |
| “Something she is telling us now is that she’s scared because something is inside of her. And it – it’s noisy. Like, you can feel it. And she always, uh, um, is touching her chest on the left-hand side” | |

**Living a medical life**

| Ongoing contact with the VAD team | “We text, we phone, we email. We are in constant contact with the clinic. They are always available” | “A lot of time while they’re in hospital, their friends are the nurses or the other interdisciplinary health professionals that they’re with” |

(Continues)
### Table 3 (Continued)

| Theme                          | Representative illustrative quotations                                                                                       | Professional caregivers                                                                                                                                 |
|--------------------------------|----------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------|
| **Living interrupted**        | “It’s actually pretty tough because there’s a lot of stuff that comes along with it even being at home, monitoring anticoagulants and if his blood wasn’t thin enough we had to give him injections in his legs, and his legs are all bruised and sore a lot of the time” | “You always have to take certain medications, you have to get your blood pressure taken, you have to come to clinic visits, even if you’re doing well. The interruptions of normal living can get quite annoying for kids” |
| **Experiencing different expertise in care** | “When he went to the [hospital], I stayed with him, I didn’t leave, because I was the only one who knew how to change the controller. Lack of knowledge made people afraid of it” | “Here in [city], it didn’t seem like they had that same level of expertise. And her dad told me that one time, he and his wife, they knew that the numbers were off, and that they needed to push fluids. And then, it didn’t happen” |
| **Negotiating restrictions**  | “He had a lot of respect for it. I think that would be really important teaching kids to respect the fact that it’s keeping you alive and it’s your heart, you don’t need to be afraid of it, you just need to be careful with it” | “We made sure she either had a big T-shirt on or a hoodie ‘cause our school has uniforms, so she could wear the uniform hoodie on top of her backpack, because she was with such little children, I didn’t want them to see the driveline” |
| **Device dependence and life limitations** | “I took her on the trampoline because the doctor said, ‘Don’t put her in a bubble. Let her live her life’. So I took her and she was like, ‘Daddy, we can’t go’. I said, ‘Yeah we can go on the trampoline. Daddy’s going to be right beside you. Daddy’s going to hold you. We’re going to jump around’. We did that and she was so, so happy. You know? So, so happy. She was like, ‘We’re doing this daddy, I can’t believe it’. I’m like, ‘Yeah we’re doing it. We can do whatever we want’. So it kind of gave her that optimism of going, ‘I’m not so limited’” | “You are tied to a machine…and all the limits that that poses on your life, um, just in a day-to-day function of, you know, running around, playing rough with your friends. Um, swimming, um, you know, and just feeling like you’re a little bit fragile and the family feeling like you’re a little bit fragile, and depending on the VAD” |
| **Negotiating restrictions and living with risks** | “We were told he could toboggan if he wanted to, but I don’t know if any parent ever would let their kid toboggan with one of these” | “Going through the typical teenage, I’m invincible years, that can be a little bit more challenging…the mistakes could cost them their life” |
| **Cost of care**               | “He wasn’t afraid of [the VAD] but he didn’t like it, he really didn’t like it. He really hated that he couldn’t go swimming, he hated that, absolutely hated that” | “If a kid has to relocate there can be many losses around that, their home, their school, their friends” |
| **Personal losses**            | “[We] are very lucky that we are a big family and we have a big support system. That’s huge”                                  | “It can be very challenging for families especially because they can’t often be off work indefinitely, so sometimes that means the family is split, sometimes the siblings have to stay back in their home community because of school.” |
| **Family efforts**             | “It all costs a lot of money…and it’s just not all covered” “We have been dipping into savings, just to cover the dressing changes. It’s easily like $400 a month. And then there are all the other costs of just trying to make life work with her on the VAD” | “If they don’t have any developmental issues, they may not qualify for some of the different programs out there and stuff. Dressings are a huge cost. Most of these kids are getting dressing changes two to three times a week by the time they’re home. And each dressing change might cost $10 or $15, which doesn’t sound like a lot, but when you add that up through the course of a month, it’s actually quite a bit” |

(Continues)
### TABLE 3  (Continued)

| Theme                        | Representative illustrative quotations                                                                 | Family members                                                                 | Professional caregivers                                                                 |
|------------------------------|---------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------|
| **Family, kinship, and community** |                                                                                                         |                                                                                 |                                                                                          |
| **Closeness of family**      | “I mean he’s a great kid, he loves me but I was always around... he couldn’t be alone away from his parents, independently and he’s a very independent kid” |                                                                                 | “So kids that are in that 8 to 12 age range, where they can’t be left alone, that’s not normal kind of growing up circumstances. The relationship with their parents can be often unique because they’re spending way more time than they normally would with a parent at that level of development” |
| **Being visible, feeling different, being different** | “There were times when people would ask him, even at the hospital here because they weren’t that familiar with it, they would ask him to take off his backpack. So, we would have to explain, well this isn’t just a backpack, this is his artificial heart and then go through the whole thing. So, it always, it was always there” |                                                                                 | “When it comes to body image kinds of aspects both for the boys and the girls, the VAD impacts the relationships that they may have with being confident, and with intimate relationships, especially with our older kids” |
| **Independence**             | “Simple things like taking a shower... he can’t do that alone. He can’t do that himself. And even something as simple as changing his clothes, it’s very difficult to do. You have to be careful in how to, um, to make sure you’re not pulling on the driveline. And I think one of the big things was the dressing change day ‘cause he knew it would be long” |                                                                                 | “But also that emotional part of their life is impacted because they’re not able to have that independence” |
| **Forming and maintaining relationships** | “It’s actually brought her a lot closer to her friends in her class. She’s got some pretty good friends and every time, like the first time we brought her back to school, man, oh my God, it was like incredible. all these kids just ran [calling her name]...they’ve been taking very well to her, and they treat her really well” |                                                                                 | “They have expressed some worries that, um, maybe some people wouldn’t choose to be their friend because they do have a higher risk of dying” |
| **Present and future living** |                                                                                                         |                                                                                 |                                                                                          |
| **Living with thoughts, questions, and uncertainty** | “Daddy, why did this happen to me?” Really tough, tough things that I have to deal with. And that’s when you sit down and you talk to her and you know and discuss a whole bunch of things and give her the comfort that she needs. I mean that’s all I can do as a parent. Just give her the comfort, talk to her, and explain things to her as best as I can” | “The other challenge is the unknown... it’s unclear when a transplant is going to happen so there’s always this, you know, sense of never really knowing what the next step in the journey is” |
|                               | “She asks questions. She talks to us about a lot, about what she’s going through... and we try to give her the response, you know, in accordance to her age” | “I think that, especially when we come into the whole destination VAD thing, it becomes a really, really tough thing. Like, to decide when is enough, enough” |                                                                                          |
| **Worry and stress**         | “And always worrying about his line being twisted or caught in a door or someone grabbing it and yanking on it, you know, it being pulled and all that, that’s very stressful” |                                                                                 | “If there’s a lot of parental anxiety around it, you can tell the kids pick up on that, and so that can be a challenge” |
| **Focusing on the future yet living the present** | “There’s been some very tough questions that she’s asked and it’s times we have to sit back and go. ‘Well, how do we answer these ones and how do we tell her?’ Because the way we’ve been trying to do it is making sure that we stay positive and keep her positive and keep her strong... so if she says something that’s a little bit negative, I give her an example of an actual positive and then she’s usually so awesome. She’ll go, ‘Yeah, you’re right daddy. I never thought of that’, and then all of a sudden the conversation goes into a different spin where she starts thinking positive and she starts feeling positive and she starts gaining this, ‘wow, I never thought of that’. So that’s what we try to do. At times it’s tough” | “We do let families and patients, when they’re old enough, know, like from the beginning, like this is a form of life-saving therapy, and we hope it’s going to be a bridge to transplant, but you know, I think we need to contemplate what’s life going to look like if for whatever the reason, you become not a transplant candidate, and you’re living on this thing” |
activity restrictions turned into a significant issue for some parents and professionals. Both families and professionals recognized that leaving the hospital and going home with a VAD involved risks. It was discussed that it was essential that children were made aware of the importance of the VAD and the need to be wary of the possibility that it can be damaged in active play. Although children with a VAD were reported as technically able to engage in most activities, families (and reportedly children themselves) often felt uncomfortable with the risks encountered in physical activities. This was particularly true for families of younger children playing with other young children who might not appreciate the critical nature of the device. Although healthcare professionals often discussed the necessity of children being under the constant watch of an adult caregiver with VAD training, some families of older children were inclined to accept risks to afford their children independence. Similarly, dietary restrictions and physical activities were variably negotiated and at times more or less enforced between families.

3.5 | Cost of care

Family and health professionals spoke about the costs of living with a VAD for a child and his or her family. A child may experience loss given daily living may be interrupted by illness and the need for specialized medical treatment. Significant time, energy, and resources on the part of the parents, siblings, and others were required to ensure that health needs were met and the child was supported to engage in activities alongside other children. A number of parents spoke how their child was undoubtedly aware of the stress these costs had on the family.

While the Canadian healthcare system partially absorbed the financial costs associated with hospitalization and implantation of a VAD, there were ongoing outpatient costs that could be left uncovered, and therefore come under the financial burden of a child's family. Both families and professionals discussed financial costs including those related to missed parental work and the cost of dressing changes. Dressing change costs varied depending on the frequency in which they were required as part of routine care or during a driveline site infection.

3.6 | Family, kinship, and community

Living with a VAD meant having family members and others in close, constant proximity. It was recognized that this closeness affected family dynamics and functioning. This experience was not necessarily negative so much as cited by families and professionals as being present for the child with a VAD, sometimes in a manner that was out-of-keeping with the child's development.

Families and professionals recognized the value of connecting children with VADs to other children with VADs or complex medical conditions) for kinship and support. Both also discussed how children with VADs seem to live within a VAD community of people oriented and trained to the device. Enlarging the VAD community had to be performed in a way that was sensitive to a child's privacy and unique situation.

Families and professionals expressed how living with a VAD was potentially frustrated by social and peer issues. The incompletely internal nature of a VAD coupled by the necessity to abide by activity restrictions, and constant supervision by a parent or qualified adult, could lead children to feel different or even isolated from their peers. Issues related to body image, identity, independence, and confidence could affect a child's intimate and public social relations, particularly in adolescence. Caregivers discussed how strategies adopted to overcome physical issues of the VAD needed to be sensitive to a child's growing personal and social identity.

3.7 | Present and future living

Family and health professionals discussed the psychological struggles that although often unvoiced could be experienced by children living with a VAD. Many families and professionals acknowledged how worry and stress experienced by parents could also affect their children. For many children and their families, heart transplantation was a hope that they lived with each day. Families talked about the importance of focusing on the present, trying to do the best they could do by their children, and retaining as much of a "normal life" as possible. How a child coped with the ongoing possibility of mortality or complications was recognized to be dependent very much on the temperament of the individual and the life circumstances of a particular child.

4 | DISCUSSION

The ability to manage heart failure with VADs outside of the hospital represents a significant technological advance. Even with successful therapy, however, children with VADs face challenges. We used qualitative methods to explore and conceptualize issues affecting school-aged children who have been discharged home from hospital with VADs.

Although the exploration of such issues benefited from a broad inclusion of caregivers from home, school, and hospital settings, there was considerable overlap in the themes identified by professionals and families. Most of the professional caregivers expressed a great deal of insight into the day-to-day home lives of these children, and families had a great deal of knowledge and concern about medical issues. Perhaps this reflected the close contact of healthcare professionals and families in our VAD Program. Alternatively, this overlap may reflect the sampling strategy to seek out caregivers who were believed likely to have important insights into the lives of children living with VADs.

Overall, it would appear that children with VADs face challenges spanning physical, developmental, and psychosocial domains. Comparisons may be drawn to other populations of technology-dependent children. For example, the ramifications for children and their families living with home ventilation are significant, with almost every aspect of life profoundly affected. Like home ventilation, there occur degrees of tension between distress and enrichment in caring for children with VADs at home. We can expect that children
with VADs may similarly benefit from interdisciplinary and coordinated plans for discharge and ongoing home support. After all, the most common reasons for failure of pediatric home care are known: lack of community and family resources, lack of financial resources, and emotional depletion of the family. And yet, we also need to be thoughtful, considerate, and wary of the balance between medical intervention and life outcomes for these children.

While children at home with VADs may have much in common with other technology-dependent children, the complications and risks of living with VADs are unique, especially when considering the way that children with VADs are connected to their devices—implanted yet exterior, mobile yet restricted, and autonomous yet dependent. There are particular issues to VADs that may impact the physical and psychosocial health of children, their well-being, and social development. The current design of the VAD for pediatric patients poses a number of unique issues related to the medical machinery itself. We may expect that some of these issues could be addressed by innovation and refinements in the design of VADs that focus specifically on making devices better able to accommodate a pediatric age range. Other issues, such as experiencing changes, living a medical life, and negotiating dependence may perhaps persist despite design innovations.

The issues raised in this study have practical importance. At the very least, these concerns may be considered as an inventory of topics that healthcare and other professionals should discuss with families and their children as they are supported at home with VADs. Understanding such issues from a child and family’s perspective will facilitate the care of these children to live as normal a life as possible yet still supporting them in their differences. These themes may also serve as topics for future research into the care of children with VADs. For example, a number of the themes speak to issues not only for children but also their families. It is recognized that children with complex medical needs most certainly can affect the health and well-being of parents, siblings, and other family members.

Limitations to this study relate to the relative silence of the voices of the children in elucidating the themes. However, this study has been completed in parallel with a qualitative research study focused on the lived experiences of school-aged VAD children. Interviewing families in psychosocial distress was out of the scope of this project, which might have impacted the themes that were identified. Perceptions were also only gathered from a relatively small sampling of caregivers based on recruitment of VAD families from a single program. Other programs potentially care for children with VADs differently such that other themes might emerge, particularly if these programs have different resources for children and families living outside of the hospital. Future research may benefit from international collaborative efforts, so best practices may be identified to support these children and their families.

Understanding the issues facing school-aged children living with VAD support in the community is critical for practitioners involved in the care of these patients and the design of programs in place to support their families. This study has provided a caregiver inventory of the challenges children face living with VADs for current practice as well as topics for future research. Ultimately, more research is needed to support children, their families, and other caregivers living with medical-technical devices in the community.

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CONFLICT OF INTEREST

The authors have no potential conflict of interests to disclose.

AUTHORS’ CONTRIBUTIONS

Courtney Petruik: Conceptualized and designed the study, collected data, analyzed and interpreted data, and approved the final manuscript as submitted; Cheryl Mack: Conceptualized and designed the study, analyzed and interpreted data, and approved the final manuscript as submitted; Jennifer Conway and Holger Buchholz: Assisted with recruitment, critically reviewed the manuscript, and approved the final manuscript as submitted; Michael van Manen: Conceptualized and designed the study, supervised data collection, analyzed and interpreted data, drafted the initial manuscript, and approved the final manuscript as submitted.

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