

The Ventricular Assist Device in the Life of the Child: A Phenomenological Pediatric Study

Qualitative Health Research
2017, Vol. 27(6) 792–804
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DOI: 10.1177/1049732317700853
journals.sagepub.com/home/qhr



Michael A. van Manen¹

Introduction

Max Van Manen

The following article by Michael van Manen is an example of the kind of phenomenological research and writing that Cathy Adams and Michael van Manen teach in their graduate Human Science Research course at the University of Alberta. This phenomenological project posed the following question: What is it like for a school-aged child to live with a ventricular assist device (VAD), an artificial heart? While a VAD child obviously may experience all kinds of strong or mixed emotions and feelings about living with a VAD for their survival, the challenge for a phenomenological study is not simply to document the psychological turmoil that each and every child in the study may undergo in different ways. Rather, the phenomenological effort is to give an interpretive account of the unique or eidetic meanings of the VAD phenomenon so that the insights offered might contribute to a thoughtful practice by health science professionals, parents, and other adults who may carry caring responsibility for the child.

Abstract

What is it like for a child to live with an artificial heart? The use of some medical therapies in children requires developmental considerations, is associated with psychosocial consequences, and calls for ethical sensitivities. A critical case is the ventricular assist device (VAD), a mechanical pump used to support the functioning of a failing heart. As a pediatric therapy, the device can be used as a temporary solution for poor heart function, a bridge to transplantation or recovery, or as a destination therapy. While the mechanical-technical operation of the VAD is well understood, the clinical-technical aspects of young people living with this device are largely unexplored. Drawing on interviews of school-aged children, the aim of this phenomenological study is to explore how a VAD may structure or condition a child's meaningful experience of their world outside the hospital. The driveline of an implanted VAD is the peripheral attachment, extruding through the skin to connect the controller-power supply. The materiality of the device may be interruptive, restrictive, and disturbing to the psycho-physical being and sense of self-identity of the child as a child. And while a child equipped with a VAD is not necessarily conspicuous among other children, the child may experience the device as an exposing presence, while living with the worry of a caregiver who takes on the role not simply of parent but of watchful health professional. A phenomenological understanding of the VAD should assist parents and caregiving health professionals knowing how to deal with specific issues arising in the life of the VAD child.

Keywords

body-heart; embodiment; ethics; lived experience; phenomenology; North America; technology

A ventricular assist device (VAD) is a mechanical pump used to support the functioning of a failing heart that is beyond the limits of conventional medical management. A variety of VAD systems are available such that a VAD may be surgically implanted or paracorporeally situated, pneumatically or electrically driven, and provide pulsatile or continuous blood flow (Potapov, Stiller, & Hetzer, 2007). Common to all of these devices is that the native heart remains in situ, connected by surgical cannula to a driving pump. This contrasts with heart transplantation whereby the failing heart is directly replaced.

VADs are proving to be an increasingly medically successful therapy in pediatric practice (Blume et al., 2016; Brancaccio et al., 2012; Fraser et al., 2012; Jeewa et al., 2010; Sharma, Forbess, & Guleserian, 2012). They may

¹University of Alberta, Edmonton, Alberta, Canada

Corresponding Author:

Michael A. van Manen, John Dossetor Health Ethics Centre,
University of Alberta, 5-16 University Terrace, 8303 – 112 Street,
Edmonton, Alberta, Canada T6G 2T4.
Email: michaelv@ualberta.ca

be used as a temporary solution for poor cardiac function, a bridge to transplantation or recovery, or as a destination therapy (Blume et al., 2016; Iodice et al., 2015; Lorts & Blume, 2015; Potapov et al., 2007). The usage of VADs is also changing with patients supported for greater lengths of time, and in outpatient rather than intensive care settings (Morales, Gunter, & Fraser, 2006). In other words, children are living with these devices at home, in school, and other everyday places. The use of these devices, however, is not without considerable risks such as bleeding, thromboembolism, infection, hemolysis, and multiorgan failure (Jefferies & Morales, 2012; Rosenthal et al., 2016).

Review of the adult literature suggests that VADs offer the promise of improved quality of life for patients (Maciver, Rao, & Ross, 2011). Despite the often sudden onset and gravity of illness necessitating utilization of VADs, many adults have the capacity to cope well with the life transitions occasioned by these devices (Overgaard, Grufstedt Kjeldgaard, & Egerod, 2012). Nevertheless, it is quite clear that living with VADs is not without challenges. VAD implantation may negatively affect a person's sense of self and bodily being (Chapman, Parameshwar, Jenkins, Large, & Tsui, 2007). Control may also be a significant issue for adults with VADs in their construction of normality, emotional state, and thoughts-feelings regarding uncertainty about the future (Hallas, Banner, & Wray, 2009). While quality of life may be improved, adult patients with VADs compared with those transplanted or explanted score lower on measures of quality of life and psychological well-being (Baba et al., 2006; Tigges-Limmer et al., 2010; Wray, Hallas, & Banner, 2007). Living with a long-term implantable VAD seems to require physical, psychological, and environmental adjustments on the part of the patient (J. M. Casida, Marcuccilli, Peters, & Wright, 2011). VAD patients rely on support from close family: parents, spouses, and children (Overgaard et al., 2012). It is also reported that caregivers who are supporting VAD patients are frequently in need of assistance themselves (Baker, Flattery, Salyer, Haugh, & Maltby, 2010; J. Casida, 2005; Egerod & Overgaard, 2012; Kaan, Young, Cockell, & Mackay, 2010).

VAD implantation in young and adolescent children is associated with psychosocial and health-related issues (Miller et al., 2015). While it would seem that pediatric patients undergoing VAD implantation are also at particular high risk for psychiatric symptoms or disorders (Ozbaran et al., 2012), it is not at all clear from the available literature what particular challenges pediatric patients with VADs face, because sending children home on devices remains an infrequent event (Conway et al., 2016). Even experienced health care professionals who work in VAD programs may lack understanding of the

needs of children who require VADs and of the problems families experience who support them (Gilmore & Newall, 2011). Children and their families may be left feeling grossly unprepared for the reality of VAD implantation (Gilmore & Newall, 2011). Therefore, a pediatric perspective is needed.

Method

The aim of this study was to gain insights into school-aged children's experiences of living with a VAD outside of the hospital. The intent was neither to psychologize nor theorize about these experiences. Rather, the goal was to understand the ways in which this medical technology becomes part of children's embodied existence. Methodologically, these dimensions of technological mediation of a child's lifeworld can be described as eidetic meaning aspects of the VAD as a technological-medical phenomenon. Phenomenology of practice, a context-sensitive form of interpretive inquiry, was used in the conduct of this study (M. van Manen, 2014).

Philosophical Methods

As the "ground-configuration" of everyday life, a technology may adumbrate human actions, mediate human perceptions, and structure human experiences (Ihde, 1990; McLuhan, 1964). Being attentive to the phenomenology of a technology requires a special methodological approach that explores the way in which a technology may shape experience as we live through it (M. van Manen, 2010; M. A. van Manen, 2015). The aim is to break through the taken-for-grantedness of daily experiences to expose the more fundamental lived meanings of these device experiences.

How technologies structure the environments in which a child spends time and the relations that unfold with others has important implications for his or her development (Bronfenbrenner, 2005). Yet, understanding the lived experiences of children is methodologically challenging. While childhood experiences should be accessible to adults who recollect childhood experiences (we have all been children, says Briod, 1989), the childhood that appears in the reminiscences of an adult "is and remains the *remembered* child, and as such is bound inextricably to the perspective of the person remembering in the *present*" (Lippitz, 1986, p. 56). The past is always conveyed via the present such that the subjective and original meaning dimensions of our childhood have been faded and fragmented, and perhaps have become even foreign to us as adults because the world in which we had existed as a child has changed or is gone.

Reflecting on the experiences of children must therefore guard against imposing an adult perspective on the

lifeworld of the child. We need human science methods to learn from the concrete and particular experiences of children themselves, and thus to consider the world as if we are *among* the children (Beekman, 1983).

Human Science Methods

VAD therapy in pediatrics remains relatively in its infancy. The Stollery Children's Hospital VAD Program is the major referral center for Western Canada and has provided for a total of nine outpatient pediatric patients since its inception in 2005 (internal audit). All school-aged VAD pediatric patients who have been equipped and discharged home on a VAD have been implanted with continuous flow devices: HeartWare HVAD® or HeartMate II® (Thoratec Corporation, Pleasanton, MA, USA). These devices essentially consist of four parts: (a) a pump that is attached to a ventricle inside the body; (b) an external controller, a small computer that monitors the pump; (c) a driveline cable, which connects the pump to the controller; and (d) a power source, which runs the pump and controller.

For this study, experiences were sought from those who currently or previously were implanted with a VAD during school age (age 7 to 18 years). Parents were welcomed to sit in on interviews to support their children in the telling of their experiences. Exclusion criteria included significant psychosocial distress or involvement in multiple studies. Through in-depth audio-recorded interviews, experiential descriptions of living with a VAD device were collected from a total of six children who ranged in age from 7 to 16 years at time of device implantation. This number is in keeping with other studies employing this methodology (M. A. van Manen, 2015).

Researching children's lived experiences poses significant challenges to the researcher (Irwin & Johnson, 2005). For example, the developmentally immature child may be simply incapable of communicating his or her inner life—reflections and memories. Some moments, events, and other happenings may only be vaguely recalled, seemingly devoid of rich experiential detail. Such remembered experiences tend to be reduced to expressions of feelings of happiness, sadness, and so forth. Conversely, the older child may be reluctant to share his or her experiences with a researcher. Adolescence, after all, is a time of individuality and secrecy. To speak openly to an adult about frustrations, hopes, and dreams requires trust.

As the researcher, I began each interview with the effort to place a child at ease to comfortably talk in a conversational manner. Strategies included conducting the interviews when possible in a familiar and secure place such as the child's home, in the living room, or a child's play place. With younger children, before orienting the

child to the nature of the interview, I began by engaging in an activity that the child enjoyed such as drawing, LEGO®, or other activities that can occur together. Initial interview questions were directed to easing the child to talk. These included everyday questions such as the name of their school, favorite toy, or a recent movie seen. Once the child seemed comfortable talking, I explained the purpose of my being there, and that I am interested in hearing what it is like to have a VAD.

I opened with very general questions to try to allow the child to direct the interview such as "can you tell me about your VAD?" This strategy was based on the literature that information obtained from free recall, or an unstructured interview, is more likely to capture the unique concerns and experiential perspective of the child, as opposed to receiving responses to questions posed from an adult perspective (Engel, 1995; Faux, Walsh, & Deatrick, 1988). As young children tend to use scripts as a means for anticipating, comprehending, and re-creating life experiences (Nelson, 1986), I transitioned to "what-happens-when" questions such as "what usually happens in the morning when you wake up with your VAD?" To flesh out free recall of events, I followed such questions with more direct queries to help translate general scripts into more personal accounts (Steward & Steward, 1996). I also asked children and parents if they had any photographs or objects related to the VAD. These cues or prompts were used to facilitate and increase the details and completeness of recall (Baker-Ward, Gordon, Ornstein, Larus, & Clubb, 1993; Price & Goodman, 1990).

Sometimes children may withhold information about unpleasant experiences because they want to avoid negative thoughts or unpleasant responses from interviewers or others. Consequently, I did constantly preface, normalize, and validate emotional responses from the children to encourage them to talk openly about such events. Appropriate to the situation, I ensured that I talked with children together and separate from their parents for such purpose. As well, I offered the participants follow-up occasions to provide the opportunity for children and their parents to recall additional facets of their experiences, commensurate with the existing literature (Poole & White, 1991; Steward & Steward, 1996).

Philological Methods

In keeping with phenomenological methodology, the text was constructed relying on analytic methods (including thematic, guided existential, linguistic, and exegetical reflection) applied to the interview material to identify and explore variant and invariant eidetic meaning aspects of the experience of living with a VAD (M. van Manen, 1990). Exemplary phenomenological anecdotes were drawn from the gathered data to assist the reader of the

research access the lived reality of the young or adolescent children's experiences. These anecdotes were constructed through editing the narratives in the direction of the phenomenal and thematic meanings by deleting extraneous materials. The goal of these methods was to gain a more direct access to the actual lived experience of the children by carefully listening and transcribing the expressions and stories of the children themselves, rather than as the children may hear the parents or health care workers talk about their lives with the VAD.

The task of writing and rewriting of the research texts is a key part of the research process as phenomenological writing involves exploring language sensitive to the phenomenon (M. van Manen, 2014). The aim of phenomenological inquiry is to achieve iconic validity meaning that the final research text (the "results") presents a recognizable human experience in textual form, resonant with the interpretive sensibility of the reader (Buytendijk, 1970).

As with any phenomenological manuscript, this text should be read tentatively with a questioning attitude. This is particularly true when the focus is on the lived experiences of children where we as adults are in part looking from the outside into the lives of children.

Ethical Issues

Permission to conduct this study was obtained from the university health ethics review board and appropriate administrative authorities. The study was structured in an attempt to minimize risks for the children and their caregivers. The children who participated in this study come from a small pool of patients who have had a VAD inserted and been discharged home. Strategies to diminish the possibility of participant identification include careful selection of anecdote examples, use of pseudonyms, and alteration of specific information that might increase the likelihood of identification. In addition, no specific contextual information is provided with regard to participants' ages, diagnoses, and family demographics as part of this study report. Informed assent from child participants and consents from all adult participants and parents were obtained.

Results

The story of a child who lives with and depends on a VAD begins with acute or chronic illness. His or her heart is failing as the consequence of cardiomyopathy, congenital heart disease, myocarditis, or some other affliction. Health prior to VAD is compromised such that life is in part composed of tiredness, irritability, breathlessness, palpitations, bodily aches, or some other symptomatology. The child is in all likelihood hospitalized; school, socializing, and extracurricular activities are disrupted.

Connected to cardiorespiratory monitors and intravenous lines for medications, the hospital may or may not be an unfamiliar place. And depending on the severity of illness, he or she may be admitted to an intensive care unit, requiring a ventilator or a more advanced extracorporeal membrane oxygenation machine.

When the option of a VAD is considered for a child, the device offers the possibility for not simply a longer life, but also the opportunity to recover semblances of what was disturbed by illness and hospital care. The VAD may allow a child to regain energy, strength, independence, and aspects of his or her life that would otherwise have remained lost. The VAD offers possibilities: leaving the intensive care, transitioning to a hospital ward, and, in time, departing the hospital to go home.

Once I got over the initial recovery from the VAD surgery. I found myself feeling better and better. I had more energy. I was less out of breath. I finally could do things just like anyone else.

After they gave me the VAD in the hospital, I was allowed to go home. I asked my friend to come over and play. We had so much fun. I almost forgot that I now had this VAD.

And yet, although a VAD may save a child's life, living with a VAD is not without changes, conflicts, and challenges for a child. While some children participating in the study seem to feel quite relaxed and comfortable talking about their VAD, for others, the experience is deeply personal. For some children, fragile emotions are slumbering just below the surface. The children may not easily express themselves about the way they are perceiving and imaging the technology to which they are attached, and that now has become part of their body, but it is not difficult to sense ambiguities and uncertainties that they experience.

I just want to get off this thing—I want to have a heart.

The actual device, inside of my chest, sometimes makes a hum, or like a kind of a buzz, and if I put my hand right into my chest I can kind of feel the vibration of it. In a really quiet room, I can hear it. Sometimes, during these times, I just can't help but think that I don't want it anymore. That I just want it taken out. That I am just done with it all.

Each child may respond differently to the implantation of a VAD, and may harbor different emotions, feelings, and sensitivities. From a phenomenological perspective, we want to understand and recognize not only the psychological feelings and emotional reactions to the VAD but how the VAD itself may give shape and form to life, body, and mind in particular ways unique to this technology. The following sections offer talk (stories, thoughts)

by children intermeshed with phenomenological reflections on the VAD experiences of these children. Of course, it is not just the language of the children that phenomenology must be attentive to but especially the underlying experiences that are expressed and hinted at in the words that the children use.

At the hand of the interview data, the reflective research text has been composed around the following eidetic themes: (a) attached dependence, (b) imperfect embodiment, (c) mechanical machineness, and (d) revealing presence. In reading this text, the reader should ask questions such as the following: What may the experience of the VAD be like for a child? What role may the VAD play in a child's everyday routine or unexpected experiences? How may the VAD affect a child's relationships with self and others?

Attached Dependence: Staying Charged to Stay Alive

For the child living with a VAD, the device itself is crucial for vitality—pumping blood through the body to maintain energy and drive.

The battery life lasts about 4 to 6 hours so during the day we get into the habit of checking and changing the battery. At night time, we do not have to worry about batteries. At night time, I am plugged in.

Although the VAD as a mechanical heart may seem like an extraordinary or invasive medical technology, it appears to become an electronic device that regulates and that is being regulated by the child. It regulates the awareness that the body has become temporally conscious and time dependent on the energy needed for the VAD to function. And it is also regulated in such a way that sleep does not have to be on worried alert, or interrupted because quite literally the body's organ is plugged into the electrical system of the child's home. "I am plugged in," says the child. This awareness betrays the sensibility that the child becomes one with the device, and the device becomes integrated with the child's body.

In the morning, or when I go out, I always make sure I have at least one full battery, and then two thirds of a battery, or a full battery on the other side. It is just part of my routine, like plugging in my phone at night. The battery life is predictable regardless of how active I am.

The child may enter into everyday habits and routines. Before going to school, going for an outing to the park, attending to errands, or engaging in other activities, battery life is needed and estimated such that it is important that the VAD has charged-energy to last the time needed. Activities may become time sensitive: having enough

time left for doing this or that. The battery measures the routine and vice versa.

Although much of the operation, maintenance, and surveillance of the device may be done by a parent or other caregiver, a child perhaps cannot help but need to learn.

The machine will actually automatically beep at you, and then it will show you like the bars on the battery. So if it goes red and it is at this bar, then you just unplug this battery and then put the new one in. It's very simple.

The battery device beeps because it warns that it is attached to the energy-demanding ventricular device inside the body. Although possibly routine, the energy demand of a VAD is of a qualitatively different nature compared with other devices. The VAD can never be allowed to fail. For the child, quite literally, "the battery life is my life," as the life-determining dependence on the device. The term *dependence* derives from the Middle French *dependre*, meaning to "hang from" or "hang down" in reliance and need. But "dependence" easily can be glossed as a superficial term. Experientially, the notion of dependence in relation to the VAD signals an immediate symbiotic embodiment that is both profoundly biological and existential. The child is attached to the controller and battery of the VAD as the condition for his or her immediate aliveness and existence.

When people ask me about the bag? I sometimes say, "My heart is in my bag." But then people don't understand that. So I end up saying, "well, there is a mechanical device in my heart, in the left ventricle, and what is in my bag is the remote and the batteries that keep me going 24/7."

Dependence on the medical invention of the VAD speaks to a complex relation of technicity (Stiegler, 1998). Humans invent a fabricated heart and produce a VAD-dependent human—in turn, the technology creates a VAD-dependent existence. Humans are both creators of and created by technology.

Still, the technical function of the VAD is fixed and expressed in the careful and deliberate layers of medical tape and bandages that secure the driveline to the child's chest. The VAD child is told what to do if the VAD were to suddenly fail: be still, conserve energy, and wait for help. Yet the child may not fully appreciate the consequences. Therefore, the phenomenological question is how does a child experience such technic dependence that often is evident in seemingly trivial and down to earth everyday happenings:

Just today I was at the clinic, and the doctor took my bag and was about to pull it away. He didn't know my VAD was in there, and my dad and I freaked out and we like just grabbed

the bag and pulled it back closer. He was like, “What happened?” And I am like, “My VAD is in here!” He was like, “Oh, I thought your line was longer.”

I was at the clinic and I actually dropped the VAD onto the floor. I don’t know what I was thinking, but before I could think what I was doing, I found myself pulling it back up onto the bench by the driveline. How stupid is that—by the driveline? Honestly, I really try not to worry about it. I try not to think what could happen. I just want to be a teenager, and enjoy whatever time I have.

Dependence may fall into background reality, only to suddenly spring to alarming notice. A child may variably feel or recognize his or her dependence on the VAD—on that which is important, consequential, and vital. For a child, however, dependence is not necessarily simply to the VAD, but rather may also express the necessity to be with caregivers.

I am ok to be alone if I am playing upstairs. I just yell down, “Battery!” when I need a change. Anywhere else, mom is right here, with me.

My dad always worries, freaks out, to make sure that everything is fine. I cannot go anywhere without someone who knows what to do if the VAD fails. I don’t take public transportation. My dad would worry too much. And to be honest, I would not feel comfortable. He drives me everywhere. The only place I am without my dad is at school. I have an emergency sheet in my bag. Everyone knows the sheet is in there. They would know what to do if the VAD were to fail. People would know what to do until my dad and the ambulance arrived.

The dependence–independence antinomy is a theme of childhood by which parents guide their children. Children learn independence and autonomy through a process of dependence. From the time a child begins to roll over or crawl, he or she expresses independence. And in response, a parent may hold the child back, moving hazardous objects out of reach, barring the child from the stairs with safety gates. As a child learns to walk or run, the parent may slow him or her down by holding a hand, reminding the child to look both ways before crossing the road. Yet as adolescence approaches, parents need to find moments to let go. Adolescence after all is a time of a developing greater self-sufficiency and exploring one’s individualism.

The potential challenge for a child with a VAD is that despite growth toward independence and maturity, he or she may continue to need help in dealing with the VAD: the insertion site, the driveline, other parts of the VAD device, and also the context of the demands and affairs of everyday life.

You need to depend on someone. It’s often the really random stuff, like trying to put cream on, or even trying to put your

pants on sometimes, especially when you are wearing skinnies. You just need a hand.

Having a shower is a huge deal. I need both my mom and dad to help so everyone gets wet. My driveline is pretty short so my dad holds the battery pack while my mom helps me wash. Last night it was so funny because my mom sprayed soap in my dad’s hair on purpose. The soap was pink and by the time we were done, drying me off and replacing the dressing, the soap was hard in dad’s hair. His hair was pink. He ended up having to have another shower to get rid of his pink hair.

Moments of dependence can surely be enjoyed, just as a child may enjoy holding onto his or her parent’s hand while going for a walk. Dependence after all is an expression of connection, bond, or contact. Dependence, however, may also be awkward, cumbersome, or difficult. Dependence for the child may be problematic—inevitably prolonging childhood and deferring adulthood. In this sense, the physiology of the embodied VAD obstructs the psychology of the child’s desire to gain autonomy, commensurate with the child’s age and development.

It’s really frustrating sometimes that I just can’t go out on my own. I mean. I always need her or someone to go with me. All I want is to just go out for a drive on my own. To be . . . like any of my friends.

Living with a VAD entails risks such as the possibilities of a bleed, a clot, or even a device failure. Independence, therefore, may come at a cost—being without the support of another at a critical moment.

I had to work on them for quite a while before they finally gave in. I told them I just needed space. I needed to be able to be left at home alone. Perhaps they just learned to accept the risks, that something could happen, but ultimately I needed to be a teenager even if that meant living with the risk of not having someone around even if I needed them.

I go out with my friends. None of them are VAD trained per se. They do know to call my mom and an ambulance if it suddenly fails. It certainly is not as safe as living in the hospital. But having some independence. It’s just a risk we are willing to take.

How a child copes with dependence, living with VAD, clearly varies from child-to-child, and family-to-family. At times, adolescent independence may be founded by simply finding someone else to depend on.

Imperfect Embodiment: I Got My Heart Under My Arm

The pump of the VAD is surgically implanted, and thus integrated or united with the user’s body. It is placed

alongside the diseased heart such that the VAD is interior and therefore has the potential to function in silence alongside the native organs—integrated as an embodied part of the body. But the embodiment of the VAD has internal and external dimensions.

I tend to brace my arm around my bag that carries the battery and controller. I clench onto it when I am out.

In addition to the implanted VAD pump, there are the battery and controller units that need to be carried as an “extra” weight. While additional to the body, neither is necessarily experienced as completely other to the body. In this respect, the VAD is phenomenologically uniquely different from a pacemaker or similar cardiac technology. A pacemaker is implanted in such a manner that it becomes taken-for-granted when functioning well, and can be passed over in silence (*passé sous silence*), as Jean Paul Sartre (1956) observed of the body in normal circumstances. The VAD becomes part of the body and yet the VAD can never really be experienced as passed over in silence as it may compel attention and cannot really be forgotten.

I never can really forget about my VAD, and it has almost become an instinct whereby I always have one hand, one arm on the VAD holding it close. When it is put down on the ground, off to the side, it actually feels kind of weird. It is as if a part of me is separate from me—over there.

Even before I was out of the hospital, it had become really just kind of a part of me, like it’s obviously a part of me now. I don’t think that I would accidentally get up out of bed and walk away without carrying it.

You always remember that it’s there, and it’s something that you are always aware of, and you are cautious about it. So, it is never like, oh I forgot I had this really.

The imperfect embodiment of the VAD can be observed when a young child with a VAD is playing on the floor—carefully yet perhaps even subconsciously playing—shifting, adjusting, and moving the battery-controller in concert with his or her play movements. Connecting the interior pump to the exterior power supply and controller device is the driveline.

The driveline goes into my chest. I don’t let people touch it. I don’t want anyone to touch it. It is connected to my heart. It hurts me if anyone pulls on it . . . it’s a sharp shooting pain.

The driveline is in some ways the most intrusive aspect of the device as it extrudes through the skin. It is the technical extension of a physical body that expresses vulnerability or an openness to harm. There is a hands-off

quality to the VAD as “something” that should not be touched that is “part of” yet also “other to” the child’s body. For the child with a VAD, he or she may be made aware of the organic–inorganic embodiment tensions, or at the very least that the body (as lived corpus) is restricted or needs to be held still when traction is placed on the line (of the artificial machine body).

The driveline is just a little short, so it’s a little hard to just put it down. Like in class, I just don’t have quite enough slack to hang it off the chair to get comfortable. My back gets sweaty from wearing it all day.

Sometimes the VAD really does get in the way. I cannot reach to help with laundry or carry heavy things because I feel the pull on the driveline. I try to be active by doing things like sit-ups, but if I stretch in the wrong way, it can really hurt. I guess it kind of holds me back.

The current design of the VAD poses difficulties for a smooth sensory embodiment, incorporating it as cyborgian technology into the bodily self-experience of the child. Yet the VAD is in part embodied nonetheless by the child. To ease embodiment, additional accessories may be needed to join the VAD smoothly to the body and restore a physical balance for a child. Ideally, the child would be able, at times, to experience his or her body in Sartre’s mode of passed over in silence. But there are many obstructions to deal with:

They made me a backpack to carry the controller and batteries. Here is where the controller goes. And then we Velcro it in like this. The driveline comes out here, under my shirt, wraps around, and is connected through the backpack zipper. The backpack is not that heavy, but it is a constant weight.

In North America and many parts of the world, the backpack is a common object in a child’s day-to-day life. For the school-bound child, we expect the backpack to contain and carry lunch, homework, and other supplies. On opening the backpack, we would not be surprised to also find child treasured items completely unrelated to school: a special coin, a toy, or other found treasure. And although the backpack is a child’s safekeeping or private place, a parent may still need to remind his or her child, “Don’t forget your backpack!” The backpack of the child with a VAD is a very different affair.

The VAD is always with me. When it’s on my back I can jump, run, or almost just forget about it. I can even go on the trampoline.

At the birthday party, they had a bouncy castle. Everyone else could jump inside except me. My dad said someone

could bump against me. Or my driveline could catch on something. That it was not safe. It was a fun party, even if I was there only to watch.

For the child with a VAD, the backpack is not a thing to be left, neglected, or forgotten once it is packed with the controller and battery. Instead, the backpack enables the VAD to be worn, fixed to the body so it is part of the body, and the child can be out there in the world as a child. Accessories help to make it work yet are still incomplete solutions.

Some things I really miss doing. Like I used to love going swimming. Just letting myself sink, submerge myself into the pool. But I cannot get my VAD wet of course. It always needs to be dry.

If it is raining out and I am trying to get home, my mum is always cautious. Like cover it and make sure you don't short circuit. It is something you worry about but at the same time you just have to kind of like go with it. You know you are somewhat protected if you have it in a bag. Still, sometimes I get worried that I didn't close the bag properly, since the wire is still hanging out, that it is not closed fully, that water will seep in.

When a child sees other children participate in such activities, the child may delight in at least being able to watch, to enjoy vicariously as the activity unfolds. Other times, the child may be jealous, angry, or perhaps simply sad. Some children may feel left out, let down, or frustrated that while able to leave the hospital, they are still unable to engage in some activities that could place the VAD at risk. Recognizing how restricted children are with their VADs is in part dependent on their own comfort and the acceptance of caregivers to risk the consequences of the VAD being damaged in active play. So, on one hand, we recognize that the VAD may allow a hospitalized child to return home and in this way the VAD creates the possibility for the child to return to his or her place of childhood and continue to grow up. Yet, on the other hand, if a child experiences being restricted perhaps this return home is incomplete. Strictly speaking, these are more the psychological than the phenomenological consequences and aspects of living with a VAD, but obviously, they are very important to consider when dealing with helping or parenting the individual child.

Mechanical Machineness: Hearing My Heart Hum

Most children, without medical conditions, are able to live their day-to-day life unaware of the health of their heart, lungs, kidneys, or other bodily organs. The interiority of the body is tacit, unvoiced, or silent. Perhaps while

running, a child may feel out of breath—panting quickly, gasping deeply. Or a child may feel the pounding of his or her heart when called on to answer a question in front of his or her classmates. Moments of bodily noticing are the exception rather than the usual manner in which a child experiences his or her body. And even in these moments, it is not necessarily the organ itself that the child notices so much as the condition of being tired or nervous. The VAD makes its presence felt and noticed in typical ways that belong to the technology of this machine.

At night, I can hear the motor kind of, it's like a washing machine or a dishwasher sound. So, I can hear that when I am trying to fall asleep, but after a while it just kind of gets washed away in the sound of everything else.

There are these moments when I just feel it. It is sore and painful. Taking a Tylenol does not help. Other times, when we are just sitting at the dinner table, we can all hear its hum.

There is inorganicity to the placement and functioning of the VAD. Pressure, displacement, or distortion may result from the forced accommodation of the pump within the limited physical confines of the child's chest. And as the VAD mechanically delivers blood by continuous flow, the heart-beat is replaced by heart-hum. For some children, this sensory mechanical machineness of the VAD may cause queasiness, nausea, and vomiting.

Sometimes I feel yucky. Not all the time but sometimes it just happens. And then I do not feel good. I feel it in my stomach, and I get sick.

The VAD can be really loud and stuff. I hear the pump through the pillow. The pillow is like an amplifier. I need music to sleep. Music to block out the sounds of the pump.

Children may variably cope with the VAD's hums, vibrations, and other inorganicities. For the child who fails to habituate to the VAD's mechanical sensuality, we may wonder whether the child's body resists embodying the VAD or rather that the VAD is mal-embodied. The term *mal-embodiment* is not meant to refer to incomplete or partial embodiment but rather dysfunctioning in the embodying of that which is to be embodied. Such moments may be evident when a child with a VAD is struggling to get to sleep at night restricted by the driveline or accidentally triggering position alarms. Sleep or pain medication may be required. Sometimes, the parent shares the child's bed to help position the child so he or she can achieve sleep.

The omnipresence of the VAD for the child becomes especially acute in a moment when the VAD is disconnected from its power source.

Last night when I went to plug into the AC, I accidentally pulled out both batteries. It made this really loud screech kind of sound. I had to plug it in right away because it started to slow down. It felt like something was just in me that just wanted to stop. I got this kind of grinding feeling, and felt light-headed. After I plugged in again, I ended up just lying in bed for a little bit, until I could feel better again.

When the VAD is in the forefront of a child's awareness, whether momentarily or constantly, we realize how the VAD, or complications from living with a VAD, may not simply restrict a child's being in a world but rather disrupt the possibility of being (being and staying alive) in its entirety.

I am dealing with a driveline infection right now. It really is a constant pain. It is just always there, and I can't seem to focus on anything else other than it.

While many children may be able to think through or distract themselves during these experiences, for others, the machineness of the VAD, that which is "other" to the child, may be experienced as a constant and dominant existential presence.

Sometimes I get scared. I can feel it—inside of me. I call my mom and dad to come. And all I just want is to just get it out.

Last night I was just sitting there, just relaxing, and paying attention to my breathing and trying to fall asleep listening to its churning motor sound when I started thinking, started worrying about it stopping. I wonder how it might all end? I think about what might happen if it simply stopped.

We hope that living with the possibility or prospect of death is an experience that is still foreign to most children's lives. And so we may wonder about the machine sounds of the VAD that impose a doom of mortality in its very machine-like presence.

Revealing Presence: The VAD Is Me and Not Me

Adults and particularly children notice when a child is different: the "always present" hip pack, shoulder purse, knapsack, or other carry bag for the control unit–power source that cannot be simply stowed may catch glances and prompt questions. Also, the driveline may come into view, out from under the shirt, drawing looks or questions. A child with a VAD may feel caught in others' gazes.

I went to a new friend's house last week and his mom began to offer to hang up my jacket and then my knapsack. She stopped, and then looked at me a little funny. I told her it is ok.

Sometimes it's hard. You know, some people just have that look, thinking, "Why isn't she removing her bag? Why does she still have it on her?"

A child with a VAD is not necessarily conspicuous among children of his or her own age. The pump is internal such that there need not be any deformity to the chest wall beyond scarring from surgery. Similarly, as described above, the control unit–power source may be hidden away in a knapsack or other carry bag out-of-view. And while the driveline visibly extends from beneath the edge of a child's shirt before connecting to the control unit, it does not necessarily catch the eye of an onlooker.

I was walking in the mall yesterday and I do not think anyone noticed me being different. Everything was hidden. No one watched or stared. I held my bag close. I felt free.

I have bought a whole bunch of different purses, and added pockets and zippers to each. I do not want to wear a fanny-pack to carry the VAD. Girls my age wear purses. I want it to look alright, you know, be fashionable so most people don't even notice it.

Out of sight, a VAD is hidden, concealed, or secreted. And for the child who carries the control unit–power source in a carry bag, the clutching hand or arm hides the VAD. The carry bag is the Old English *hyde* "skin" covering the VAD so the child can fit in like any other child. From this perspective, the carry bag or other made accessory assists to not simply facilitate the embodiment of the VAD but also preserves the childhood of the child by allowing him or her to fit in socially just like any other child. Concealment, however, is not perfect.

People are really interested in the VAD so I find I often get questions about it. Or people ask whether they can see it or a part of it. Usually it is ok. I do not mind. But other times, I just wish they would stop looking at me.

A child may welcome questions because they allow him or her to show-off his or her VAD, a thing that is so very unique, sophisticated, and important. Yet, sometimes, even an innocent question about a child's VAD may be unwelcome, irritating, or upsetting. Such questions do not necessarily come just from strangers but also from those closest to the child.

During the day, my mum always comes and checks on me when I am playing in my room. She asks if I am ok, asks if I am hungry, and checks to make sure the VAD is not caught on anything. At nighttime, after reading stories, she checks on it again. There are other times too when I see her watching me. Just yesterday I caught her watching me, standing in the doorway, she asked if I needed a snack even though I had just eaten.

The VAD is a “thing”: it needs to be watched and checked on as a “piece” of technology. But the VAD is also a part of the child such that it is not simply the VAD that needs attention but also the child. Not unlike checking for hunger, fickle, or impatient appetites, parents do check on the VAD as part of caring for their child. While it is not unusual, and it is certainly important for a parent to check in on his or her child, we may wonder how the VAD may influence, disturb, or reconcile the relationship of parent and child. How does the child experience the incessantly watchful eye of the parent? How does the child experience being seen, or even failing to be seen, when the VAD is being monitored? How may the child experience a constant parental supervision?

My dad plays hide-and-seek with me. I am much better at hiding than him although sometimes I think he lets me find him. My mom once cleaned out one of the closets so I had a new hiding spot. At first my dad just looked in my usual spaces, in the shower and behind the couch. But he could not find me. His voice changed and he began calling my name really loud. “Here I am!” I answered. He ran and gave me a huge hug. We have not played hide-and-seek since.

The VAD is not necessarily simply revealing but also transformative of the relationship of parent and child. The child may find himself or herself constantly being minded, observed, worried about, or watched. Whether this means the nighttime bed becomes the shared bed of parent and child to allow a constant watching of the child, or whether the bedroom door is simply never closed to ensure that the parent can hear the child in activity or sleep.

The VAD itself may announce medical issues with its low battery noises or other audible alarms. So, although a child may or may not appreciate the potential risks of living with a VAD or potential permanence of death that would ensue if the VAD were to fail, a child with a VAD may have to put up with the experience of always being seen and unable to ever experience perfect privacy. While a parent lives with worry (of infection, stroke, or death that a VAD entails), a child lives with the worry of a worrying caregiver who takes on the role not simply of parent but also nurse, physician, or other watchful health professional.

We have other routines. We need to check my blood levels, to adjust my medication levels. I also need to keep track of how much I drink and what I drink. Sometimes it really is just too much, and I wish so much I could have a break from it all.

This year, it feels like I have spent just as much time at hospital as at home.

For some children with VADs, we may wonder to what extent the child with a VAD actually is able to leave

the hospital, especially with the ongoing contact with the medical team, and of course the always present possibility for readmission. In this sense too, the eidetic meaning of a VAD has a unique phenomenology in that it carries the ambivalence of being me or just part of me. A child with a VAD lives in a different relation to the technology than a child with an artificial limb or joint. An artificial leg can become “me” such that it is no different from my other natural leg. But a VAD always poses the question of my own heart or the artificial heart of the VAD—as mine or as an intruder (Nancy, 2000).

Conclusion

From speaking with children dependent on a VAD, there is no doubt that the device offers more than a solution for poor cardiac function: A VAD allows a child to recover certain aspects of his or her childhood, to leave the hospital and return home, in a way that is changed from the life before the device was implanted. While children may have different experiences with the VAD, depending on their physical constitution, psychological condition, and many other contingencies related to home circumstances, school environment, and community contexts, a phenomenology of the VAD reveals what makes the experience of living with a VAD recognizably unique.

The phenomenology of the VAD includes experiential determinations of meanings: (a) The meaning of the VAD is characterized by a unique kind of dependency, unlike other technological dependencies that people may experience. The staying of the charged functioning of the VAD is literally the staying alive. The child is implanted with a pump and attached to a computer-power unit to keep blood flowing. Dependency is not simply an expression of the device but also the network of people the child may need to depend on. Critically, the VAD disrupts and modifies the normal childhood developmental antinomy of becoming independent through dependence. (b) Imperfect embodiment is the experience of organic–inorganic features of the VAD. While this most vital organ, the VAD heart is carried by the child literally under the arm, over the shoulder, or on a hip belt; the VAD is also experienced as organically part of the child. (c) Machineness is the experience of living the body-heart as mechanical and of the VAD as a machine presence. In cinemas today, we are nonplussed by scenes of a cyborg unhinging an arm or some other part of the body to fix or repair it as if it is just a piece of machinery. Yet that is how the VAD is “made” as a body-device that vibrates, hums, or grinds. The child may experience the VAD as a functioning or malfunctioning device that is not simply outside-to-the-body and is also not simply inside-of-the-body. (d) The VAD child cannot help but experience his or her personal and social identity and sense of self with the VAD technology. The

visible components of this cardiac technology may necessitate the felt need to hide the VAD device.

Recognizing these possible phenomenological meanings of the phenomenon of the VAD, we need to consider pedagogically how the VAD while being a medical device is also a “child’s device.” The phenomenology of the device may suggest ways of dealing and living with the child who must deal and live with the VAD. We need to allow children to treat the VAD not simply as a “thing” but rather as a part of their body, recognizing that as a bodily device, it may be nonetheless difficult for a child to actually embody it. For example, when a caregiver examines the VAD, he or she should consider handling the VAD much like they would touch other parts of the child’s physical body. After all, a child with a VAD is dependent on the device, and while embodiment is imperfect, there is sensuality to the device that reflects a part of the child’s body experience. Watching the care with which a child holds the driveline as it is bandaged by a caregiver shows the sensuality of the VAD device just as much as when a child withdraws when someone reaches to touch it.

Without a doubt, there are significant emotional and psychosocial burdens of living with a VAD. Caregivers need to support children whether it means making sense of the life situation, dealing with the worries of medical complication, or simply living with the sensations of the mechanicity of the device. Just like in other medical contexts, we need to consider how children can habituate to the VAD so they can focus on the ordinary and routine aspects of their lives even in the context of dependency and uncertainty (Stewart, 2003). Recognizing the VAD may also touch on a child’s personal and social identity, we need to reflect on how we can allow the child to be simply a child, yet also reconcile that the child cannot be without their device. While facilitating normalization may be a goal for a particular family, the goals of any particular child with a medical illness must be understood (assessed, explored, and supported) individually (Guell, 2007; Nicholas, Picone, & Selkirk, 2011; Rehm & Bradley, 2005).

Technologically, efforts to improve pediatric VADs certainly need to focus on ensuring the safe support of cardiac function, diminishing or mitigating the risks of medical complications. Yet, designers need to also prioritize a pediatric perspective for VAD design, recognizing that the design of the medical devices may influence interactions with others and the experiences of children themselves (Høiseth, Keitsch, & Hopperstad, 2014; Hussain, 2011). Reducing the size, weight, and exterior aspects of the device seem like logical next steps to truly make VADs pediatric in scale with the long-term hope of moving in the direction of a fully implantable device that functions with minimal hums, vibrations, and other inorganicities to allow a full and uninterrupted embodiment.

Until such time of innovation in pediatric VAD technology, a great deal of thoughtfulness and consideration needs to be given to how the driveline is made to extrude through the skin, secured at the site, and the length of the driveline itself. For example, the driveline needs to have enough length to allow a child to distance himself or herself away from the VAD during such activities such as showering balanced against the problems that could arise if the VAD line is too long and catches, pulls, or tugs in active play. We may wonder whether the VAD line could somehow be made to be retractable or otherwise modifiable for the activity of a child. How the VAD driveline is actually secured to the skin is also important. The driveline needs to be secured, so gentle pulls or tugs are not necessarily felt as pain, yet at the same time, the child continues to have awareness if inadvertent stronger tension is placed on the line. Ultimately, considerations around the driveline need to consider individualities of a particular child with regard to activity, maturity, size, and so forth.

Accessories and other aides need to be designed from a “function” perspective such that the VAD is embodied. Backpacks are the perfect solution because they allow a VAD to be truly affixed to the child, restoring embodiment. But not all children want to wear backpacks. Consideration therefore also needs to be given to “form,” such that accessories need to be made to allow the device to be hidden or at the very least worn in a way that suits a particular child. Made accessories should be of high enough “grade” to allow the skin to breathe, protect the device from water, yet offer flexibility to movement.

The focus of this study has been on the phenomenology of living with a VAD: how it may structure or condition children’s meaningful experiences of their world outside the hospital. In large part, this has to do with the design and functionality of the technology of the VAD. Beyond the VAD, we need to be cognizant that children who live dependent on a VAD may have other medical complications or psychosocial issues that may eclipse the experience of the VAD itself. Experiences related to VAD-associated medical complications while not the focus of this study may be significant events in a child’s life. These other experiences that are not necessarily unique to VAD technology-dependent children, but rather may also be shared by those with other chronic illnesses or medical conditions, deserve discussion, reflection, and study. It was apparent in talking to these children how much medical, social, and developmental support they need and do receive. We need to continue to support research for such children, and in particular, support work done for and with them, so they can transition to live their lives as children in their homes, and in the future as they mature to adults. This is particularly true for the child who is not simply technology-dependent but also

transitioning home to complex sociocultural situations (Cohen, 1999).

Understanding young and adolescent children's experiences who require support with a VAD is paramount to the practice of practitioners involved in the tactful care of these patients and the programs in place to support them.

Acknowledgments

I am very grateful to the children who generously shared their experiences for this study. I also thank Catherine Adams, Holger Buchholz, Jennifer Conway, Courtney Petruik, and Cheryl Mack for their helpful comments on reviewing this article.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research has been funded by the generous support of the Stollery Children's Hospital Foundation through the Women and Children's Health Research Institute (WCHRI).

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Author Biography

Michael A. van Manen, MD, FRCPC (Peds, NICU, CIP), PhD, is a clinician researcher in neonatal-perinatal medicine, Department of Pediatrics, University of Alberta, Edmonton, Alberta, Canada.