


Patient and Family Experience in a Multidisciplinary Clinic for Children With Single-Ventricle Heart Disease

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Abstract

Children with single-ventricle heart disease (SVHD) are at risk for morbidity across multiple organ systems. A single-ventricle multidisciplinary clinic (SVMDC) may address complex health-care needs by providing access to, and coordination among, pediatric subspecialties. However, the patient and family experience of multidisciplinary care for SVHD remains unexplored. We e-mailed a 26-question survey to families after an SVMDC visit, which included evaluation with subspecialists from cardiology, pulmonology, gastroenterology, neuropsychology, and pediatric psychology, as well as social activities during clinic. Responses were anonymized to protect privacy, and data were analyzed quantitatively and qualitatively. Over 3 years, 22% (27/122) of families completed the survey. Overall, families' experiences were positive, with 100% reporting that they would recommend the SVMDC to others. Qualitative themes emerged regarding logistics, multidisciplinary care, key takeaways from clinic, and connection-making with other families. A multidisciplinary clinic demonstrated overall acceptability and perceived benefit to families of children with SVHD. Considerations for mixed experiences regarding financial commitment and connection-making among parents are discussed, as are the benefits of the synergy achieved through multidisciplinary care.

Keywords

hypoplastic left heart syndrome, single ventricle, Fontan, multidisciplinary clinic, family experience survey

Introduction

Over the past few decades, surgical advances have resulted in markedly increased life expectancies for children with single-ventricle heart disease (SVHD) (1). This has been accompanied by an increase in morbidity across various organ systems as a result of “downstream” consequences of the Fontan circulation. Children with Fontan physiology are at risk for liver fibrosis, protein-losing enteropathy, plastic bronchitis, sleep-disordered breathing, and neurocognitive impairments, in addition to cardiac morbidities such as heart failure and arrhythmias (2-6). They are also at risk for internalizing and externalizing problems related to experiencing a life-limiting chronic illness from birth (7), which impacts their health-related quality of life (8) and parent and family well-being (9). Morbidities often emerge over time, particularly during the second decade of life, imparting a need for close, ongoing monitoring of patients with SVHD by various subspecialties disciplines across the life span. We created a single-ventricle multidisciplinary clinic (SVMDC)

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at our quaternary care institution to increase our SVHD patients' access to subspecialty care, offer a standardized model of multiorgan surveillance and testing, and increase patient engagement with the medical team and other families.

Multidisciplinary clinics are becoming common in tertiary and quaternary care settings and have been demonstrated to improve subspecialty care utilization (10) and clinical outcomes (11) while reducing hospital-based charges (12,13). However, little data exist regarding families' experiences of pediatric multidisciplinary clinics. This is concerning, as family perception of care is a strong predictor of adherence with treatment recommendations as well as clinical outcomes (14,15). The National Quality Forum has identified patient/family experience surveys assessing perceptions of interdisciplinary care coordination as one of their top 5 prioritizing measures, highlighting this area as critical for emerging research (www.qualityforum.org). Additionally, documenting high patient/family satisfaction is one avenue of demonstrating evidence of quality care to payers and accrediting organizations (16), an important consideration in an evolving health-care landscape and shift toward outcome- and value-based payment.

As such, our SVMDC prospectively collected data regarding patient/family experiences with our clinic. We hypothesized that families would have a positive overall perception of the SVMDC and that this would be related to perceiving the format as convenient, and the opportunities to meet other families that might not take place in a standard clinic setting. We also wondered if the financial and time commitments would be perceived as worthwhile and whether families might perceive receiving care from 5 specialties at once as efficient, or overwhelming.

Materials and Method

Prior to each patient's SVMDC visit, he or she completed a variety of tests according to a prospectively applied clinical care pathway (17), including cardiopulmonary exercise testing, echocardiogram, pulmonary function testing, liver ultrasound, and blood work. During the clinic visit, each patient was seen for a 20- to 30-minute consultation by a provider from gastroenterology, pulmonology, neuropsychology, and pediatric psychology. These specialties were chosen for inclusion in the clinic on an empirical basis, considering the various organ systems experiencing downstream complications due to Fontan circulation.

After the patients were evaluated, the providers convened for about 30 to 45 minutes to discuss the patients, while the children (patients and siblings) participated in a group scavenger hunt lead by Child Life Specialists, and the parents had coffee while discussing their experiences having a child with SVHD, facilitated by a licensed hospital social worker. During the last hour of the half-day clinic, the cardiologists met with each family to share the multidisciplinary care plan based on the team's discussion. Families and their referring

cardiologists received detailed care plans 1 to 2 weeks after their clinic visit.

The SVMDC Family Experience Survey was designed by our subspecialty providers and a survey design expert in our institution's Patient-Family Experience department. Questions were phrased in an unbiased manner; questions were written at about a sixth-grade reading level; and standard anchors were used for multiple-choice items. The survey was built in REDCap (18), a secure HIPAA-compliant web application for data capture, and included 26 questions, some of which automatically populated additional follow-up questions based upon the response.

There were 6 sections to the survey. The first section asked about the patient/family's experiences prior to the clinic visit, including Likert scale response items about ease of scheduling and how prepared the patient/family felt before the visit, as well as free-response items regarding any surprises the patient/family may have encountered, and what, in hindsight, they wished they would have known prior to coming to the clinic. The second section of the survey asked about the clinic visit itself, including Likert scale response items regarding the helpfulness of information and resources obtained during the clinic visit, provider communication effectiveness and listening skill, and satisfaction with the parent and child group activities. Free-response items asked for specific feedback about the parent and child group activities. The third section of the survey asked patients/families to rate on a Likert scale how helpful it was to meet with each subspecialty provider and asked in a free-response item if there were any additional specialties they would have liked to meet with during the multidisciplinary clinic. The fourth section of the survey asked patients/families to rate on a Likert scale their experience of the multidisciplinary clinic with regard to general convenience, creation of a comprehensive care plan, communication among their providers, opportunities to connect with other families, and connection to other resources in the hospital. The fifth section of the survey asked about the time after the multidisciplinary clinic visit, including yes/no questions about whether follow-up appointments were obtained and care plans received. There were also free-response items regarding billing and financial impact and whether parents' view of their child's SVHD were impacted after the clinic visit. The sixth and final section of the survey asked patients/families to rate on a Likert scale their overall satisfaction and likeliness to recommend the multidisciplinary clinic to other patients/families of children with SVHD and a free-response item to obtain any additional comments or feedback (Supplemental Figure 1).

After each SVMDC, the survey was e-mailed to the families via the e-mail address provided in the chart for the parent or guardian. If the parent or guardian did not respond to the survey initially, a reminder e-mail was sent 1 week later. All families included a child, adolescent, or young adult with SVHD who had completed the Fontan palliation series and was at least 1 year post-Fontan procedure. The only exclusion criterion was inability to read English by the

Table 1. Qualitative Feedback Excerpts by Theme.**I. Logistics**

"It was an expensive visit. Prior testing the day before and doctor visits the day of added up to over \$2000 in bills"

"The clinic was helpful, and I was grateful for the visit. The downside to the visit is I was charged a \$200 room charge for the visit and I had to pay a co-pay for each doctor. I did not realize the clinic would cost so much."

II. Multidisciplinary care experience

"The only real negative for me was the glut of feedback. There was SO much information, including follow-up recommendations, it was hard to swallow it all in one sitting."

"So awesome to have my child evaluated by multiple areas on the same day; I feel for the first time that my child was evaluated as a whole being not just by one entity. Such great information as all disciplines are connected."

"It gave us a great baseline for our child's health. There were some things tested that we didn't even realize needed to be monitored. It gave us a much better understanding of why it's so important to look at our child's overall health, not just the heart."

III. Connecting with other families in clinic

"Regarding the parent group, positive isn't the word I would use to describe it, rather powerful and helpful!"

"We did not like having to speak with other families about our feelings during our "break" . . . it made us very uncomfortable."

"Our daughter can be a little shy at first and kind of attached to, her mom. But she said the [child group activity] was nice, seeing other kids that are like her and not being asked about the scar on her chest."

IV. Key takeaways from clinic

"My heart felt happy to hear 'let your child live a normal life, they will tell you when they need limits' . . . as far as the sheltering helicopter parent aspect. It's something I as a parent needed to hear to help my child's overall well-being . . ."

"I realized, tricuspid atresia does not define my child; she can be anything she wants to be in life, with determination and hard work."

V. Overall impressions and likelihood to recommend to others

"Kids [with complex medical needs] like ours NEED this big picture support."

"It is the best way for our kids to get the best care, in the least amount of time, and it puts less stress on the child [compared to multiple, separate appointments]."

person who would be filling out the survey, due to an inability to create an analogous survey of equal quality in multiple languages. All surveys were anonymous, to protect patient and family privacy. This project was approved by the institutional quality improvement project review board. Survey responses were collected and analyzed via REDCap. Specifically, qualitative data analysis techniques including content analysis, data organization, and pattern detection were utilized with the free-response text items, while descriptive statistics were calculated for multiple-choice response items.

Results

Over 3 years, 122 survey invitations were sent to families seen in our SVMDC. This represented 81% of Fontan patients followed at our institution. Twenty-seven surveys were completed, yielding a response rate of 22%. Each response represented a different family, as the link could only be used once. Survey responses were anonymous, so participant descriptive data are unavailable. Because of the anonymous nature of the survey, we were unable to compare characteristics of responders versus nonresponders. Regarding our SVMDC sample, the youngest age of a patient seen in our multidisciplinary clinic was 5 years, and the oldest was 26 years. Although the age range was wide, 83% of patients were between the ages of 5 and 15 years. Furthermore, in this population, morbidities across organ systems do not necessarily correlate with age, so the need for multidisciplinary surveillance is consistent across age groups. Multiple themes emerged from the rich qualitative and quantitative data collected through this survey (Table 1).

Logistics

Logistical topics assessed included ease of scheduling, time commitment, and financial burden. No families reported difficulties with scheduling the multidisciplinary clinic visit and the associated tests, with 74% describing the process as "very easy," 19% as "pretty easy," and 7% as "neither easy nor difficult." The time commitment invested by each family (including travel time and preclinic testing) was substantial, with 19% of families investing more than 12 hours, 26% investing between 8 and 12 hours, 44% investing 4 to 8 hours, and only 11% investing less than 4 hours. Nevertheless, 100% of families reported that their multidisciplinary clinic visit was worth the time invested. The experience of the financial side of the multidisciplinary clinic visit, in contrast, was highly variable. Just over half of the sample reported no financial burden associated with the visit (52%); however, 26% reported substantial financial cost (see Table 1) and 22% were unsure as they had not yet received a bill at the time of completing the survey.

Multidisciplinary Care Experience

Regarding their experience with multidisciplinary care, families uniformly reported greater convenience in seeing the various specialties during one clinic visit instead of separately, with 96% describing the multidisciplinary clinic as "much more convenient" and 4% as "somewhat more convenient" compared to separate appointments. Furthermore, all families perceived the multidisciplinary clinic approach as having either a "very positive" (93%) or "somewhat positive" (7%) effect on communication among specialty

Table 2. “During the Clinic Visit You Met With a Number of Providers. How Helpful Did You Find Each?”^a

Specialty	Not Helpful	A Little Helpful	Somewhat Helpful	Pretty Helpful	Very Helpful	I Did Not Meet With This Specialty
Cardiologist	0 (0%)	0 (0%)	2 (7%)	3 (11%)	22 (82%)	0 (0%)
Gastroenterologist	1 (4%)	1 (4%)	3 (12%)	3 (12%)	14 (53%)	4 (15%)
Pulmonologist	0 (0%)	2 (8%)	1 (4%)	5 (19%)	15 (57%)	3 (12%)
Neuropsychologist	0 (0%)	1 (4%)	2 (8%)	2 (8%)	18 (68%)	3 (12%)
Pediatric psychologist	1 (4%)	2 (8%)	0 (0%)	4 (16%)	14 (54%)	5 (18%)

^aData presented as n (%). Total N = 27.

providers regarding their child’s care, and the providers’ ability to think about the “big picture” or the “whole child” (“very positive” [82%], “somewhat positive” [18%]).

Family ratings of the helpfulness of meeting with each specialty are presented in Table 2; overall, each specialty received positive ratings. Additional specialties that families would have liked to have had the opportunity to meet with in the multidisciplinary setting included nutrition and neurology. Families unanimously endorsed that it was “very easy” to present their questions and concerns to the various specialty providers and felt that the information they received was presented “pretty well” (33%) or “very well” (67%) with regard to the family’s ability to understand it. The majority of families felt they received the right amount of information (92%), although some felt that they simply received too much information to process in one visit (8%; see comment in Table 1), and none felt they received too little information.

Connecting With Other Families in Clinic

One of the unique aspects of our multidisciplinary clinic was the opportunity provided for parents and children to connect with one another through group activities, while the providers convened to discuss and coordinate plans of care. This was designed to provide a chance, during what would otherwise be downtime, for families to meet others with a shared experience and identity as an SVHD family, as well as to provide peer support to decrease a patient or family’s sense of isolation related to the child’s rare cardiac condition. However, feedback from families regarding the acceptability of this format was mixed. The group for patients and siblings, which involved a hospital scavenger hunt with a Child Life Specialist, was uniformly well-received, with 100% of participating families reporting a “positive” (37%) or “very positive” (63%) experience. In contrast, families had different experiences with the parent group; while 63% described their experience as “very positive,” 25% described their experience as “neutral,” and 13% as “very negative.” Comments ranged from appreciating the opportunity to make connections with other parents to feeling uncomfortable in a “support group” setting and sharing that they would have preferred to spend the downtime in their clinic room, discussing the information received during the

clinic visit with their family (Table 1). Overall, when asked about their experiences connecting with other families through the multidisciplinary clinic (which included informal connection-making during clinic time in addition to the structured groups), families’ feedback was variable, with 43% viewing this aspect of the clinic as “very positive” or “somewhat positive” and 53% viewing it as “neutral” and 4% viewing it as a “very negative” experience.

Key Takeaways From Clinic

Takeaways from clinic for our patients and families included tangible benefits (eg, referrals for follow-up appointments, informational handouts, and resources) as well as intangible benefits (eg, new information, new care plan, or a new perspective on their child with a single ventricle). Regarding tangible benefits, all families endorsed receiving resources in at least one of the following domains: resources for parents (eg, advocacy groups), resources for children (eg, educational suggestions), community resources (eg, congenital heart disease–specific camps), or other resources, and 100% of families reported these resources to be “helpful.” Of the 27 families, 22 reported having been referred for at least 1 follow-up specialty care appointment as a result of the clinic visit (eg, neuropsychological evaluation, a sleep study, or psychotherapy). Regarding the intangible takeaways from the multidisciplinary clinic visit, a sizable minority of families reported feeling less worried about allowing their child to participate in sports or other physical activities (30%; while 70% reported no change and 0% reported feeling more worried). Similarly, 33% of families reported that they would allow their child to participate in more sports and physical activities as a result of the information gained during their multidisciplinary clinic visit (while 67% reported no change and 0% reported allowing their child to participate in fewer activities).

Overall Impressions and Likelihood to Recommend to Others

Overall, all families indicated that they were either “very satisfied” (67%), “pretty satisfied” (26%), or “somewhat satisfied” (7%) with their multidisciplinary clinic visit. Furthermore, 81% reported that they were “very likely,” and

the other 19% “likely” to recommend the clinic to other families of children with SVHD (see Table 1).

Discussion

Families of children with SVHD endorsed positive experiences with an SVMDC. Common themes regarding the advantages of the SVMDC included greater convenience of seeing multiple specialty providers in one visit, appreciation for interdisciplinary collaboration in providing multi-system recommendations for their child, and opportunities to obtain helpful resources that families might not have otherwise received. The patient and sibling hospital scavenger hunt was universally highly rated. Additionally, families felt it was helpful to see each subspecialty provider included in the clinic (cardiology, gastroenterology, pulmonology, neuropsychology, and pediatric psychology). These data suggest that a similar grouping of specialties could be considered for future SVMDCs at other institutions. Several families also brought up the utility of including a dietician in clinic. Because of this feedback, our SVMDC has obtained access to a dietician who is available to consult during clinic.

Mixed feedback was received regarding the financial burden of the SVMDC visit. Although we did not collect data regarding insurance coverage, we speculate that many of the individuals who reported not receiving a substantial bill from the visit may be recipients of public insurance or low-deductible private insurance, while those who reported receiving a larger bill may have a higher deductible plan without supplemental or secondary coverage. Although addressing systemic disparities in health-care coverage is beyond the scope of our clinic, we have endeavored to systematically refer families with private insurance to our institution’s insurance preauthorization department, which provides upfront estimates of the financial commitment for an SVMDC visit. We have also worked with families who voiced concerns about their deductible to schedule all testing, clinic visits, and procedures within the same year. Based on previous studies, it is likely that visiting each of our SVMDC’s subspecialties separately would incur more hospital charges than receiving care in our SVMDC (12,13).

The parent group, which occurred during clinic downtime, evoked mixed feedback, with some individuals describing it as a “powerful” and “helpful” experience, and others sharing that it made them “very uncomfortable.” Although peer support can be beneficial, it must be offered at the right time for families who are interested, and interest may not be universal. Additionally, scheduling limitations kept the groups smaller than would be ideal (around 3-4 families). We included the parent and child groups in our SVMDC design based on literature, suggesting that semi-structured groups with parents and children experiencing medical conditions have been perceived as helpful (19,20). However, the reason we designed and implemented this family experience survey was to obtain this type of feedback, specific to our SVHD population. Although we continue to

offer the parent group during clinic downtime as an option, we now emphasize the optional nature of group participation and do not assume that all parents will participate. Additionally, we continue to offer different forms of patient and parent support at our institution, including both internal family education events and external family connection events.

Comments from families in our survey highlighted an appreciation for “value-added” services, such as receiving tangible resources and referrals that emerge from synergistic multidisciplinary evaluation and team discussion. At our institution, we previously demonstrated multiple-fold increases in subspecialty evaluation and identification of medical, neurocognitive, and psychological comorbidities for our SVHD population, a manifestation of care pathway adherence, since the launch of our SVMDC (17). A significant minority of families also endorsed feeling more comfortable letting their child with SVHD take on more independence and participate in more physical activities after visiting the SVMDC, which may have long-lasting effects on these children’s physical and emotional well-being (21).

Limitations

Limitations to the present study include a low response rate to our survey, which may hinder generalization of our findings. Because survey responses were anonymous, we are not able to ascertain whether nonresponders differed from responders on clinical or demographic characteristics. However, relatively low response rates are common in patient and family experience surveys, particularly in pediatric medicine (eg, response rates of 11.5% (22) and 10.2% (23)) or when a family member is ill (24). We hypothesize that this may be related to increased stressors and time demands experienced by families managing a childhood chronic illness. Although our overall number of responses was modest, we feel that the data adequately capture parent experiences at our site with data saturation reached for qualitative analysis. Based on our experience, we would suggest that future studies should consider administering patient/family satisfaction surveys at the end of the clinic visit, which might result in a higher response rate.

Conclusion

Our data demonstrate overall acceptability and perceived benefit by families for a multidisciplinary clinic including 5 pediatric subspecialties for the SVHD population. Qualitative and quantitative analysis of patient and family feedback suggests that the whole of a multidisciplinary clinic may be greater than the sum of its parts, with the most prominent advantages being the opportunities for synergistic interdisciplinary collaboration; connection-making among patients, siblings, and families (for those who wish to do so); and obtaining referrals and information about their child’s medical condition that may impact the way the family thinks about their child with SVHD. Authors’ Note

Adel K. Younoszai and Michael V. Di Maria are co-senior authors. This project was approved by the institutional quality improvement project review board. The survey was approved by the institutional quality improvement and research panel, which determined that informed consent could be waived due the anonymous nature of data collection in the context of evaluating routine clinical care.

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Supplemental Material

Supplemental material for this article is available online.

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