Cardiology in the Young

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Making it work for all: equity in single ventricle monitoring

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Original Article

Cite this article: Sooy-Mossey M, Tallent S, Hornik CP, Park S, Schmelzer AC, Reynolds L, and McCrary AW (2024) Making it work for all: equity in single ventricle monitoring. *Cardiology in the Young* **34**: 2303–2310. doi: 10.1017/S1047951124026908

Received: 10 July 2024
Revised: 24 September 2024
Accepted: 29 September 2024
First published online: 23 October 2024

Keywords:
Health equity; single ventricle; mobile applications; race; language; socioeconomic

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Abstract

Background: Interstage monitoring programs for single ventricle disease have been developed to reduce morbidity and mortality. There is increased use of telemedicine and mobile application monitoring. It is unknown if there are disparities in use based on patient socio-demographic factors. *Methods:* We conducted a retrospective cohort study of patients enrolled in the single ventricle monitoring program and KidsHeart application at a single centre from 4/21/2021 to 12/31/2023. We investigated the association of socio-demographic factors with telemedicine usage, mobile application enrollment and usage. We assessed resource utilisation and weight changes by program era. *Results:* There were 94 children in the cohort. Patients with Norwood and ductal stent had higher mean telemedicine visits per month (1.8 visits, $p = 0.004$), without differences based on socio-demographic factors. There were differences in application enrollment with more Black patients enrolled compared to White patients ($p = 0.016$). There were less Hispanic patients enrolled than Non-Hispanic patients ($p = 0.034$). There were no Spaish speaking patient's enrolled ($p = 0.0015$). There were no patients with maternal education of less than high school enrolled and all those with maternal education of advanced degree were enrolled ($p = 0.0016$). There was decreased mobile application use in those from neighbourhoods in the lowest income quartile. There were decreased emergency department visits with mobile application monitoring. Mean weight-for-age z-scores had increased from start to completion of the program in all eras. *Discussion:* Differences were seen in mobile application enrollment and usage based on socio-demographic factors. Further work is needed to ensure that all patients have access to mobile application usage.

Introduction

Adoption of home interstage monitoring for infants with single ventricle heart disease has been shown to improve morbidity and mortality in the high-risk period between Stage 1 and Stage 2 palliation.[1] In recent years, due to both the COVID-19 pandemic and improved technology, there has been increased use of telemedicine, electronic tracking, and other strategies for interstage monitoring.[2,3] Within single ventricle heart disease, it has been shown that patients with Black race[4,5] and Hispanic ethnicity[4,6] have increased mortality compared to their White peers overall. Specifically during the interstage period, Black patients have an increased risk of mortality, though this has not been shown in Hispanic patients.[7,8]

At our institution, the management of single ventricle patients has undergone significant advancements in the last four years. Beginning in 2019, we initiated protocolised scripted nurse phone calls every two weeks with patient caregivers across our interstage cohort augmenting our previous "3-ring binder" self-reporting plan. These nurses liaised with the primary cardiologist or single ventricle primary contact at Duke in case of any concerns. The program evolved in the fall of 2021 to include nurse practitioner-driven billable telemedicine visits every two weeks, alternating with in-person visits with the primary cardiologists, replacing scripted phone calls. During the telehealth encounter, the nurse practitioner reviewed red flags, oxygen saturations, weights, and feeding plans, prescribing appropriate interventions. The nurse practitioner provided additional support by facilitating communication between the surgical centre at Duke and primary cardiologists and coordinating care with community resources. In April 2022, the single ventricle program developed and piloted an English-only version of an application-based reporting software, Duke Kids Heart App (*KidsHeart)*, recording biometric and symptom monitoring in real-time with alerts generated via email to the single ventricle team when patients fall outside of set parameters, allowing for trend monitoring and intervention in conjunction with telehealth visits at the same frequency used previously. The data within the application are monitored by the single ventricle nurse practitioner and nurse during business hours with an alert sent for abnormal value input. The data from *KidsHeart* integrate into the telemedicine visit medical record documentation, enhancing communication and understanding between caregivers and the medical team about the child's health status. While our program and other single ventricle monitoring programs has been shown to be overall acceptable to families, there are no data investigating if there is equitable availability and usage of these resources.

With the expansion of technology-dependent resources and access to care, we sought to investigate if there were differences in the use of the single ventricle monitoring program with telemedicine visits and *KidsHeart* usage based on various socio-demographic factors including patient race, ethnicity, primary language, insurance status, maternal marital status, maternal education level, and paternal education level to ensure patient equity.

Materials and methods

Study design

This was a single centre retrospective cohort study of patients enrolled in the single ventricle monitoring program and *KidsHeart* at Duke University Hospital from April 21, 2020, to December 31, 2022. Inclusion criteria for the single ventricle monitoring program during this time period included Norwood procedure, hybrid Norwood, patent ductus arteriosus stents, pulmonary artery bands, or other type of surgical shunt. Exclusion criteria included death before Glenn or other second surgical procedure. For the study period, there was an overall mortality of 1.45% at home and 3.62% for those admitted from home then died in the hospital for an overall mortality rate of 5.07%. Patient demographics and clinical data were extracted from the electronic health record via chart review. *KidsHeart* data were extracted from the mobile application. Study data were collected and managed using Research Electronic Data Capture electronic data capture tools hosted at Duke University. This study was approved by the Duke Health Institutional Review Board.

Study variables

Patients were divided into the era in which they were monitored: nurse-led phone call and paper binder (Era 1), nurse practitioner-led telemedicine-based monitoring (Era 2), or telemedicine plus potential for *KidsHeart* monitoring (Era 3). Patient demographics collected from electronic health record included race, ethnicity, insurance type, and primary language. Maternal marital status, maternal education level, and paternal education level were collected from birth certificate data within electronic health record where available. Distance to hospital was calculated using patient home address as recorded in the electronic health record and address of main hospital campus. Patients were matched to their census tract using home address. This was then used to find census tract median family income based on Census 2020 data.[9] Clinical data collected included index cardiac surgical procedure. Time in the single ventricle monitoring program was calculated using initial discharge date to date of Glenn operation or next surgical procedure removing shunt-based circulation. The number of emergency department visits and inpatient admissions, as well as the count of telemedicine visits or nurse phone calls, were gathered through documentation in the patient's chart. Patient weight-for-age z-scores were collected at time of initial hospital discharge and at time from discharge from monitoring via chart review. *KidsHeart* enrollment was collected from the application. If patients were enrolled in the application, the number of days logged in the application was collected as any type of interaction for that day. The total number of red flags marked during the interstage period was collected from the application.

Statistical analysis

The demographic characteristics were summarised for categorical variables using counts and percentages by era in the single ventricle monitoring program. Mean number of interstage telemedicine visits and mean number of telemedicine visits per month in the program were calculated and stratified by patient demographics. These were compared using *t*-test when there were two categories and analysis of variance when there were greater than two categories. Patient race was coded as Black, White, or Other, which included "Other" "2 or More races". Patients with race or ethnicity of "Not reported/ Declined" were not included. Counts of patients enrolled in the app compared with those not enrolled in the app were calculated and compared with Fisher's exact test. *KidsHeart* usage was assessed by calculating the percentage of days logged into the application compared to possible eligible days. This was stratified by patient demographics, and means were compared using *t*-test when there were two categories and analysis of variance when there were greater than two categories. To assess differences in resource utilisation across program eras, the mean number of admissions and emergency depNEIGHartment visits was calculated. These were compared across eras using analysis of variance. Additionally, incidence rate ratios were calculated for emergency department use and admissions. Mean weight z-score was calculated at the time of discharge and at the end of time in interstage program. Difference of these was calculated for each era. Differences across eras were compared using analysis of variance.

Results

There was a total of 94 patients monitored in the single ventricle program during the study time period. Of these, 28 patients participated during the nurse only phone call era (Era 1), 19 patients participated in telemedicine monitoring without *KidsHeart* monitoring (Era 2), and 47 patients participated in telemedicine with potential *KidsHeart* monitoring (Era 3). Socio-demographic factors including race, ethnicity, insurance type, language, distance to hospital, maternal education level, paternal education level, and neighbourhood income quartile are shown in Table 1. There was a similar distribution of race, ethnicity, language, maternal education level, paternal education level, and neighbour income quartile across the three eras. There were a greater portion of patients with Medicaid (79%) and living<50 miles (46%) from the hospital in Era 1. There were a greater portion of married mothers (57%) in Era 3. There was a similar distribution of initial procedure types across the three eras, with only one hybrid Norwood occurring during the study period.

Telemedicine usage

The mean number of telemedicine visits or phone calls was 7.0 (standard deviation 4.0) for Era 3, 6.8 (standard deviation 3.7) for Era 2 and 1.9 (standard deviation 2.4) for Era 1. Adjusting for the number of months the patient was monitored, the mean number of telemedicine visits was 1.7 (standard deviation 0.9) for Era 3, 1.2 (standard deviation 0.7) for Era 2, and 0.3 (standard deviation 0.5) for Era 1 ($p < 0.0001$).

No difference was seen in telemedicine usage by patient demographics of race, ethnicity, insurance type, language, distance to hospital, maternal marital status, maternal education level,

Table 1. Cohort demographics by era

	Era 3 App available (4/12/22–12/31/22) *n* = 47	Era 2 Telemedicine Monitoring (11/1/21–4/11/22) *n* = 19	Era 1 Binder/Phone Calls (4/1/21–11/1/22) *n* = 28
Patient Race			
American Indian/Alaskan Native	0	0	0
Asian	0	0	0
Black	30% (14)	32% (6)	39% (11)
White	49% (23)	26% (5)	43% (12)
Native Hawaiian or other Pacific Islander	0		0
Two or more races	4% (2)	11% (2)	4% (1)
Not Reported/ Declined	6% (3)	16% (3)	0
Other	11% (5)	16% (3)	14% (4)
Ethnicity			
Hispanic	15% (7)	32% (6)	18% (5)
Non-Hispanic	77% (36)	68% (13)	82% (23)
Not reported/ declined	8% (4)	0	0
Insurance Type			
Medicaid	51% (24)	53% (10)	79% (22)
Private	47% (22)	42% (8)	21% (6)
Other	2% (1)	5% (1)	0
Language			
English	92% (43)	90% (17)	93% (26)
Spanish	8% (4)	10% (2)	7% (2)
Distance from Hospital			
<50 miles	30% (14)	26% (5)	46% (13)
51–100 miles	40% (19)	26% (5)	29% (8)
>100 miles	30% (14)	47% (9)	25% (7)
Maternal marital status			
Married	57% (27)	47% (9)	36% (10)
Not married	21% (10)	21% (4)	46% (13)
Unknown	21% (10)	32% (6)	18% (5)
Maternal Education Level			
<HS	6% (3)	11% (2)	7% (2)
HS graduate	19% (9)	21% (4)	21% (6)
Some college	19% (9)	16% (3)	25% (7)
College graduate	24% (11)	16% (3)	18% (5)
Advanced degree	8% (4)	5% (1)	11% (3)
Unknown	24% (11)	32% (6)	18% (5)
Paternal Education Level			
<HS	4% (2)	0	7% (2)
HS graduate	23% (11)	21% (4)	14% (4)
Some college	13% (6)	16% (3)	14% (4)
College graduate	23% (11)	21% (4)	7% (2)
Advanced degree	4% (2)	0	0
Unknown	32% (15)	42% (8)	57% (16)

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https://doi.org/10.1017/S1047951124026908 Published online by Cambridge University Press

Table 1. (*Continued*)

	Era 3 App available (4/12/22–12/31/22) $n = 47$	Era 2 Telemedicine Monitoring (11/1/21–4/11/22) $n = 19$	Era 1 Binder/Phone Calls (4/1/21–11/1/22) $n = 28$
Median Neighbourhood Income			
Quartile 1	11% (5)	32% (6)	36% (10)
Quartile 2	30% (14)	32% (6)	18% (5)
Quartile 3	36% (17)	21% (4)	14% (4)
Quartile 4	23% (11)	16% (3)	32% (9)
Initial Procedure			
Norwood	43% (20)	37% (7)	36% (10)
Hybrid Norwood	2% (1)	0	0
PDA stent	28% (13)	32% (6)	21% (6)
PA bands	19% (9)	32% (6)	25% (7)
Other	9% (4)	0	18% (5)
Enrolled in App			
Yes	72% (34)	–	–
No	21% (10)	–	–
Withdrawn	6% (3)	–	–

Demographics of patient cohort stratified by era in which patient received care.
SV = single ventricle, HS = high school.

paternal education, or neighbourhood income (Table 2). There was a statistically significant difference in the number of telemedicine visits per month based on the initial procedure that patients underwent with patients with a Norwood procedure (1.8 visits per month) and ductal stent (1.8) having the highest number of telemedicine visits ($p = 0.004$).

KidsHeart usage

There were 34 families (72%) who enrolled in *KidsHeart* versus 10 families (21%) declining to enroll during the study period. Differences were seen in *KidsHeart* enrollment status by race, ethnicity, language, and maternal education level (Figure 1). Black patients were most likely to enroll in *KidsHeart* compared to other race categories ($p = 0.016$). There was a greater proportion of non-Hispanic patients enrolled than Hispanic patients ($p = 0.034$). There were no patients who spoke Spanish as their primary language enrolled ($p = 0.0015$). There were no women with less than a high school education who enrolled and conversely all women but one with some college or more education were enrolled ($p = 0.0016$).

Of those patients who enrolled in *KidsHeart*, those from the lowest neighbourhood income quartile had significantly less application usage with a mean use of 21% of days (standard deviation 26.8, $p = 0.003$) There was no difference in the percentage of days they logged in the app by race, ethnicity, insurance type, distance from the hospital, maternal marital status, maternal education level, or paternal education level (Figure 2). Overall, patients indicated a red flag in the app less than one time (mean 0.91, standard deviation 1.36) during the monitored period.

Hospital resource utilisation by program era

There was a mean of 0.14 (standard deviation 0.28) emergency department visits per month in Era 3, 0.18 (standard deviation 0.20) in Era 2 and 0.21 (standard deviation 0.38) in Era 1 ($p = 0.60$). Incidence rate ratios for emergency department usage were 0.45 (confidence interval 0.26–0.78) for Era 3 versus Era 2, 0.72 (confidence interval 0.42–1.23) for Era 3 versus Era 1, and 0.062 (confidence interval 0.038–0.103) for Era 2 versus Era 1. There was a mean of 0.34 (standard deviation 0.38) admissions per month in Era 3, 0.29 (standard deviation 0.24) in Era 2 and 0.40 (standard deviation 0.34) in Era 1 ($p = 0.55$). Incidence rate ratios for admissions were 1.30 (confidence interval 0.70–2.52) for Era 3 versus Era 2, 1.42 (confidence interval 0.84–2.45) for Era 3 versus Era 1 and 1.09 (confidence interval 0.55–2.10) for Era 2 versus Era 1.

The mean weight-for-age z-score at the time of patient discharge were low overall at –1.76 (standard deviation 1.50) for Era 3, –1.72 (standard deviation 1.25) for Era 2, and –2.26 (standard deviation 1.23) for Era 1. Mean weight-for-age z-score had increased for each era with a mean weight-for-age z-score change of + 0.42 (standard deviation 1.04) for Era 3, +0.98 (standard deviation1.04) for Era 2 and + 1.10 (standard deviation 1.13) for Era 1 ($p = 0.023$).

Discussion

This study describes the evolution of single ventricle interstage monitoring at a single academic centre examining its use by patients and families by various socio-demographic factors. There was no difference in telehealth monitoring by socio-demographic

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Table 2. Telehealth usage by demographics

	Number of interstage telehealth visits ($n = 66$), Mean (SD)	*P-value*	Mean number of interstage telehealth visits / month in program ($n = 66$)	*P-value*
Patient Race		0.51		0.76
Black	7.8 (4.2)		1.6 (0.9)	
White	7.0 (3.9)		1.6 (0.6)	
Other	6.1 (3.6)		1.4 (0.9)	
Ethnicity		0.41		0.30
Hispanic	6.1 (3.8)		1.8 (0.9)	
Non-Hispanic	7.1 (4.0)		1.5 (0.9)	
Insurance type		0.32		0.97
Medicaid	7.4 (4.0)		1.6 (0.9)	
Private	6.4 (3.5)		1.6 (0.8)	
Language		0.72		0.98
English	6.9 (3.8)		1.5 (0.9)	
Spanish	7.5 (4.5)		1.5 (0.9)	
Distance to Hospital		0.19		0.31
<50 miles	5.7 (3.5)		1.2 (0.9)	
50–100 miles	7.8 (4.4)		1.7 (0.6)	
>100 miles	7.1 (3.4)		1.5 (1.0)	
Maternal marital status		0.098		0.76
Married	8.0 (4.2)		1.7 (0.7)	
Not married	5.9 (2.8)		1.6 (1.2)	
Maternal Education Level		0.70		0.56
<HS	6.2 (3.6)		1.2 (0.9)	
HS graduate	7.5 (3.5)		1.7 (1.0)	
Some college	6.9 (4.5)		1.8 (0.8)	
College graduate	8.6 (4.7)		1.6 (0.8)	
Advanced degree	6.4 (2.6)		2.1 (0.7)	
Paternal Education Level		0.099		0.69
<HS	3.0 (2.8)		1.7 (1.9)	
HS graduate	9.7 (4.3)		1.8 (1.0)	
Some college	6.9 (4.1)		1.4 (0.8)	
College graduate	6.9 (3.1)		1.8 (0.7)	
Advanced degree	8.0 (2.8)		1.3 (1.0)	
Median Income		0.67		0.69
Quartile 1	7.1 (3.4)		1.6 (1.1)	
Quartile 2	7.2 (4.9)		1.7 (0.8)	
Quartile 3	6.1 (3.2)		1.4 (0.9)	
Quartile 4	7.2 (3.7)		1.5 (0.8)	
Initial Procedure		0.69		**0.004**
Norwood	7.1 (3.1)		1.8 (0.6)	
Hybrid Norwood	4.0 (0)		0.8 (0)	

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Table 2. (*Continued*)

	Number of interstage telehealth visits ($n = 66$), Mean (SD)	*P-value*	Mean number of interstage telehealth visits / month in program ($n = 66$)	*P-value*
PDA stent	6.9 (4.8)		1.8 (1.1)	
PA bands	7.6 (4.3)		0.9 (0.5)	
Other	4.8 (2.9)		1.0 (0.8)	

Demonstrates the mean number of telehealth visits attended by patients when telehealth was available (eras 2 and 3) stratified by patient demographic.
HS = high school.

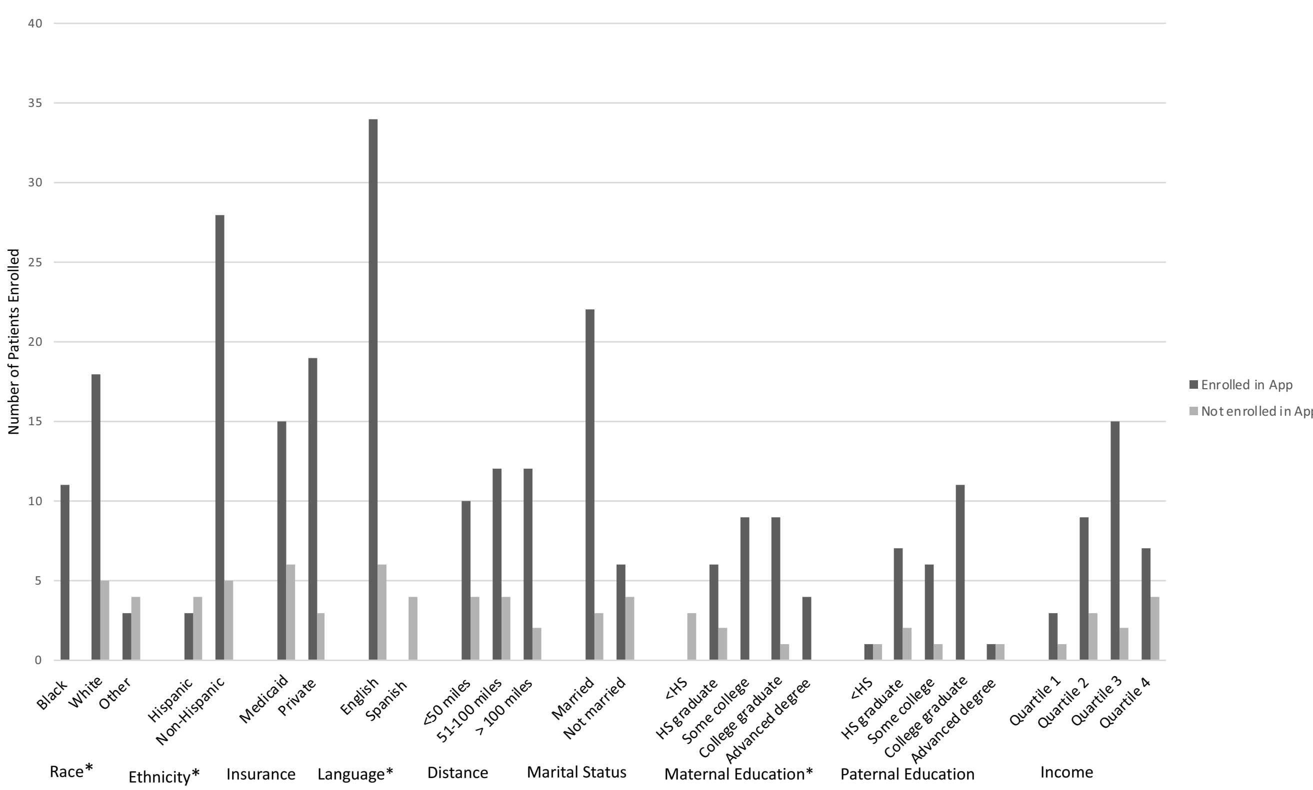

Figure demonstrates the number of patients enrolled versus not enrolled in mobile monitoring application stratified by patient demographics.
** indicates statistically significant finding*
HS= high school

Figure 1. Demographics by mobile application enrollment.

factors; however, patients who underwent Norwood and ductal stent procedure had more telehealth visits than those undergoing other initial staging procedures. There were differences in *KidsHeart* application enrollment based on patient race, ethnicity, language, and maternal education level. There was decreased mobile application usage among those from the lowest neighbourhood income quartile.

With the increased use of technology through telemedicine and mobile applications, there is both the potential to improve or worsen existing health disparities. In this cohort, we did not see disparities in telemedicine usage; however, we did find that there was differential application enrollment based on maternal education level, which has been seen in other populations.[10,11] This may be due to many factors including literacy, lack of access to internet services, and lack of access to technologies.[12] Importantly, caregivers needed to have access to a smart phone or tablet to utilise the application as devices were not supplied to them. Other programs have successfully employed device-loan strategies to reduce this barrier.[13] Focusing on reliable internet, community level programs exist to help families with internet access, and as such more emphasis should be placed on highlighting these barriers and local resources early to facilitate successful home care. Patients have identified these same barriers and solutions, but also note that some patients and families might not ever be willing and/or able to incorporate digital technology.[14] Thus, ensuring high quality, low-tech options remain essential.

Additionally, literacy may be in important factor in decision to uptake application-based technology, which includes various types

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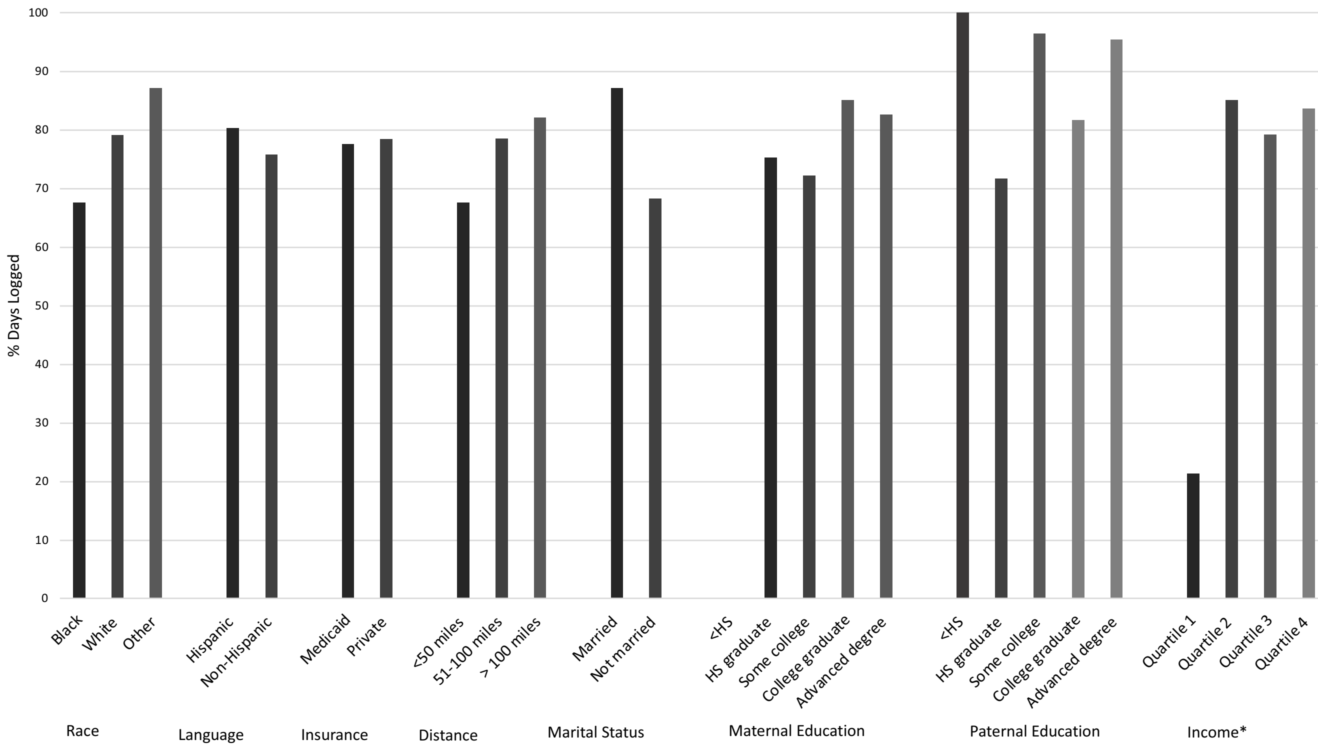

Figure 2. Application usage by demographics.

of literacy, such as general literacy, health literacy, digital literacy, and numeracy. In general, individuals have poorer outcomes across a variety of conditions when they have lower literacy.[15] When looking at health literacy, one in four adults have low health literacy, which may greatly impact how parents make decisions for their children, including choosing to participate in mobile monitoring.[16] This barrier may be improved upon by introducing the mobile application to families early in the process. Currently, the *KidsHeart* app may be downloaded while patients are still admitted so parents can practice using it with staff assistance and increase their comfort prior to discharge.

We found that there were no patients enrolled in the application who spoke Spanish as their primary language, which was anticipated as the pilot of *KidsHeart* was only offered in English. Language presents a unique challenge when implementing any form of telehealth monitoring as synchronous telemedicine visits require an available interpreter and mobile application usage require translation into the patient's preferred language. These can be costly barriers to equitable implementation. We recognised this early in the *KidsHeart* application development and are currently working on translation into Spanish to increase access to these families. Decisions about translation should considered with patient population served by each centre. While language barriers pose challenges, it is crucial to explore feasible alternatives to ensure equitable access for all patients. We found that there was a difference in mobile application enrollment based on patient race and ethnicity, which may be attributed to Latinx families not participating in the app due to language availability.

We found that there was decreased mobile app usage after enrollment by those from the lowest neighbourhood income quartile. This may be due the challenge with connectivity as above. Reassuringly, there was no difference in telehealth monitoring or application usage once enrolled by other socio-demographic factors. This is consistent with previous research in which telemedicine monitoring visits have been shown to be acceptable to both families and cardiologists in a small cohort of infants with single ventricle disease.[2] The implementation of telemedicine visits helps to reduce the burden of transportation insecurity and childcare arrangements often experienced by patients.[17] When looking at mobile health monitoring, one study showed that while there were disparities in infant weight gain during the interstage period based on neighbourhood social vulnerability index, a neighbourhood level measure. This disparity was eliminated with the use mobile application monitoring, suggesting there is benefit for all patients with inclusive engagement.[18]

While there was no differences seen in incidence rates of admissions, there was a decrease in the incidence rates of emergency department visits with of the addition of mobile application monitoring to a telemedicine based program to the lowest level of all three eras. This may be due to the ability to identify and address issues sooner as an outpatient through easier, real-time communication. Alternatively, Era 2 saw an increase incidence of emergency department visits that could point to the early phases of the program as monitoring and access were increasing. When assessing mean weight-for-age z-scores, there was an improvement across all types of single ventricle monitoring suggesting that any type of monitoring intervention will help to improve weight gain. There was a greater increase during era 1; however, this group also had the lowest mean weight-for-age z-score at discharge leaving the most room for improvement.

There are some limitations to this study. It was a single centre study; however, the cohort of patients included was large for a single ventricle population. Given the overall small size of this population, the sample size may not have been large enough to identify additional disparities and larger, multi-institutional studies are warranted. Additionally, when assessing if there were emergency departments visits or inpatient admissions, we had access only to our health system's electronic health record. It is possible that patients received care at other institutions which we were not able to detect. As mentioned above *KidsHeart* during this time period was part of an ongoing research study and may have affected choice to participate.

This study demonstrated that within a single ventricle monitoring program at an academic centre there was equal use of telemedicine by patient socio-demographic factors; however, there were differences in those who enrolled for mobile application monitoring. It is essential to consider that the increased use of technology within healthcare has the potential to both increase and decrease known health disparities. When designing and implementing new technology-based interventions, we must work to ensure that we are optimising the benefits for all our patients and providing equitable access and care.

Acknowledgements. None.

Financial support. This work was supported by the National Heart, Lung, and Blood Institute of the National Institutes of Health under by under award for Postdoctoral Training in Cardiovascular Clinical Research (5T32HL069749).

Competing interests. None.

Ethical standard. The authors declare that they comply with appropriate institutional and international guidelines for ethical guidelines. This work was approved by the Duke University Institutional Review Board.

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