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Original Article

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Abstract

Objectives: There are limited data documenting sources of medical information that families use to learn about paediatric cardiac conditions. Our study aims to characterise these resources and to identify any disparities in resource utilisation. We hypothesise there are significant variations in the resources utilised by families from different educational and socio-economic backgrounds. **Methods:** A survey evaluating what resources families use (websites, healthcare professionals, social media, etc.) to better understand paediatric cardiac conditions was administered to caretakers and paediatric patients at Morgan Stanley Children’s Hospital. Patients with a prior diagnosis of CHD, cardiac arrhythmia, and/or heart failure were included. Caretakers’ levels of education (fewer than 16 years vs. 16 years or more) and patients’ medical insurance types (public vs. private) were compared with regard to the utilisation of resources. **Results:** Surveys completed by 137 (91%) caretakers and 27 (90%) patients were analysed. Websites were utilised by 72% of caretakers and 56% of patients. Both private insurance and higher education were associated with greater reported utilisation of websites, healthcare professionals, and personal networks (by insurance $p = 0.009$, $p = 0.001$, $p = 0.006$; by education $p = 0.022$, $p < 0.001$, $p = 0.018$). They were also more likely to report use of electronic devices (such as a computer) compared to those with public medical insurance and fewer than 16 years of education ($p < 0.001$, $p < 0.001$, respectively). **Conclusion:** Both levels of education and insurance status are associated with the utilisation of informative resources and digital devices by families seeking to learn more about cardiac conditions in children.

With a rising global prevalence and median incidence of approximately 8 per 1,000 live births, CHD continues to impact millions of children and their families worldwide.^{1,2} Counseling families of patients diagnosed with CHD involves in-depth explanations of potentially complex anatomical structures and often requires cardiologists to provide additional digital and non-digital resources such as diagrams, medical websites, and printed information.^{3,4} A comprehensive understanding of the diagnosis is paramount to a parent’s decisions related to the management of their child’s CHD.⁵ Prior studies have reported that internet-based CHD-specific health information accessed online influences parents’ decisions about their children’s healthcare.⁶ Despite widespread Internet use, online health literacy remains low with many parents reporting a lack of familiarity with the types of resources available online, inability to assess the quality of those resources, and distrust in the information they find.^{6,7} Furthermore, many families prefer to receive more CHD education from their child’s cardiologist than what is generally provided.⁸ As information available through digital platforms continues to expand, the impact of health literacy – particularly as it pertains to information seeking – on health outcomes is a topic of growing importance.^{9,10}

Prior studies have reported that the Internet, paediatric cardiologists, and general paediatricians are some of the most common sources of health information for parents of children diagnosed with CHD.^{6,11} However, little is known about the specific types of digital and non-digital resources families utilise to bolster their understanding of their child’s CHD. Furthermore, whether any differences exist in the types of health information families use has been largely underexplored.

In this study, we address this gap by characterising the types of informative resources utilised by families of paediatric patients following up for care at the Congenital Heart Center at Columbia University Medical Center/Morgan Stanley Children’s Hospital of New York. We assessed if any significant differences exist in the use of resources between families of varying socio-economic strata defined by health insurance type and the education levels of caregivers. The findings from this work add to the existing body of knowledge dedicated to understanding the impact of social determinants, particularly health literacy, on paediatric health disparities and inequities.

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Materials and methods

A cross-sectional survey-based study was conducted from October, 2021 to December, 2021 to assess both digital and non-digital sources of medical information used by families to better understand cardiac conditions in children. Surveys were reviewed by co-authors prior to the start of the study to optimise the readability and appropriateness of the survey for patients and their caretakers at the study centre. Caretaker and patient surveys were also assessed using the readability statistics tool within Microsoft Word. The Flesch-Kincaid Grade Level of the caretaker survey and paediatric survey was 5.5 and 5.4, respectively. Eligible study participants were identified on the day of the paediatric patient's follow-up visit at the congenital heart center. Caretakers of patients who were previously diagnosed with CHD, cardiac arrhythmia, and/or heart failure were included in the study. Caretakers who do not speak English or Spanish and caretakers of patients with heart transplants were excluded. Patients 12 years of age and older with capacity to provide assent and complete the study survey were approached at the same time as their caretakers (Supplementary S9–S10). The primary exposure for the study was caretaker socioeconomic status as estimated by the patient's medical insurance type. The secondary exposure for the study was caretakers' levels of education. Insurance coverage was stratified into two groups: public insurance plans, specifically CHIP or Medicaid plans, and private insurance plans, such as employer-sponsored plans or those from the marketplace. Caretaker level of education was stratified into two groups: those with fewer than 16 years of education (less than high school, high school graduate, some college, or 2-year degree) and those with 16 or more years of education.

Surveys were administered via a study iPad containing the Qualtrics survey link or via participants' own devices since a QR code for the survey was also provided. A member of the research team was available to answer participants' questions while taking the survey. Study participants had the option of completing the study survey in either English or Spanish (Supplementary S5–S8). Participants also had the option to have the study survey read aloud if they otherwise could not use the research iPad or were limited by low visual acuity. The survey included demographic questions on age, education level, gross annual household income, language(s) spoken at home, and the patient's health insurance type. Clinical questions included the cardiac diagnosis, time since diagnosis, number of previous hospitalisations, and number of previous surgeries. The study survey also assessed access to the Internet and digital devices such as laptops and smartphones. Participants were then asked to indicate which types of digital and non-digital sources of medical information they may have used to learn about paediatric cardiac conditions. The first of these questions asked participants to select which general resources – websites, healthcare professionals, social media/online groups, personal contacts, printed sources, and/or video platforms – they may have used at least once to learn about the heart. The study survey then assessed more specifically the types of websites (i.e., commercial sites, government sites, etc.), healthcare professionals (i.e., general paediatricians, paediatric cardiologists, nurse practitioners etc.), social media/online groups (i.e. Facebook, Reddit, etc.), personal contacts (i.e. family, friends, etc.), printed sources (i.e. textbooks, pamphlets, etc.), and video platforms (i.e. YouTube, TikTok, etc.) participants may have used to learn more about their diagnosis and which they utilised the most. Final survey questions assessed participant satisfaction with the number of resources received, how often participants had access to information in their native

language and participants' perceptions on how often the information they obtained agreed with doctors' recommendations. Answer choices were structured as five-point Likert scales with one representing "always" or "extremely satisfied" and five representing "never" or "extremely dissatisfied."

Statistics

Statistical analyses on completed study surveys were conducted using Stata Statistical Software: Release 17 (College Station, TX: Stata Press. StataCorp. 2019). Pearson's chi-square test and Fisher's exact test were used to assess for potential associations between insurance status and caretaker education level with the utilization of resources to learn about paediatric cardiac conditions. The study protocol was approved by the Institutional Review Board at Columbia University (protocol AAAT7433).

Results

Demographics

Surveys were administered to a total of 151 caretakers and 30 patients and were completed by 137/151 (91%) caretakers and 27/30 (90%) patients for an overall response rate of 91%. The median caretaker age range was 31–45 years of age. Among caretakers, 58/135 (43%) reported their race as White and 107/137 (78%) reported their gender as female. Of those who completed the survey questions on insurance and education, 83/135 (61%) of patients were covered by public medical insurance plans and 52/135 (39%) had private medical insurance plans. Sixty-three of 128 (49%) caretakers reported having completed at least 16 years of schooling or through a 4-year degree, and 65/128 (51%) reported fewer than 16 years of education or less than a 4-year degree. Seventy-nine of 136 (58%) caretakers reported speaking only English at home; 110/137 (80%) had access to a device (such as a laptop), 131/137 (96%) had Internet at home, and 126/136 (93%) used a smartphone. The median patient age range was 15–17 years of age. Among patients, 11/26 (42%) reported their race as White and 14/27 (52%) reported their gender as male. Additionally, 17/27 (63%) of patient responders reported speaking only English at home; 26/27 (96%) had access to a device (such as a laptop), 27/27 (100%) had internet at home, and 27/27 (100%) used a smartphone (Table 1).

General resource utilisation by caretakers and paediatric patients

Websites and healthcare professionals, such as general paediatricians, paediatric cardiologists, and advanced practice providers, were the most popular resources caretakers reported using at least once to learn about paediatric cardiac conditions (websites 98/137 [72%], healthcare professionals 106/137 [77%], Table 2, Fig. 1). For caretakers who specifically indicated which types of websites they utilised, 58/74 (78%) reported using commercial websites such as WebMD. For caretakers who specifically indicated which healthcare professionals they consulted, 55/98 (56%) reported consulting someone other than the paediatric cardiologist to learn about the heart. Furthermore, 66/130 (51%) of the caretakers reported that their primary resource for learning about paediatric cardiac conditions was healthcare professionals, such as paediatric cardiologists, general paediatricians, or advanced practice providers (Supplementary Table S1). Patients also frequently reported consulting healthcare professionals (18/27 [67%]), and more than half reported using websites to obtain health information (15/27

Table 1. Caretaker demographic data by patient insurance type and caretaker education level^a; paediatric patient demographic data^a

Demographic characteristics	All caretakers (n = 137)	Paediatric patient insurance status		Caretaker education level (years)		Demographic characteristics	All paediatric patients (n = 27)
		Public insurance (n = 83)	Private insurance (n = 52)	< 16 (n = 65)	16+ (n = 63)		
Age (years)							
16–30	26 (20.47)	24 (30.77)	2 (4.17)	20 (33.33)	5 (8.33)	12–14	6 (27.27)
31–45	69 (54.33)	40 (51.28)	28 (58.33)	30 (50.00)	35 (58.33)	15–17	11 (50.00)
46–60	30 (23.62)	12 (15.38)	18 (37.50)	9 (15.00)	19 (31.67)	18–20	4 (18.18)
61–75	2 (1.57)	2 (2.56)	0 (0.00)	1 (1.67)	1 (1.67)	21–23	1 (4.55)
Gender							
Male	26 (18.98)	13 (15.66)	13 (25.00)	15 (23.08)	9 (14.29)		14 (51.85)
Female	107 (78.10)	67 (80.72)	38 (73.08)	48 (73.85)	53 (84.13)		10 (37.04)
Gender not listed	1 (0.73)	0 (0.00)	1 (1.92)	0 (0.00)	1 (1.59)		2 (7.41)
Prefer not to say	3 (2.19)	3 (3.61)	0 (0.00)	2 (3.08)	0 (0.00)		1 (3.70)
Race							
American Indian/Alaskan Native	2 (1.48)	2 (2.44)	0 (0.00)	2 (3.12)	0 (0.00)		0 (0.00)
Asian Native Hawaiian or other Pacific Islander	9 (6.67)	5 (6.10)	4 (7.84)	5 (7.81)	4 (6.45)		2 (7.69)
Black or African American	24 (17.78)	18 (21.95)	6 (11.76)	13 (20.31)	10 (16.13)		3 (11.54)
White	58 (42.96)	26 (31.71)	32 (62.75)	21 (32.81)	36 (58.06)		11 (42.31)
More than one race	10 (7.41)	7 (8.54)	3 (5.88)	5 (7.81)	5 (8.06)		4 (15.38)
Unsure	11 (8.15)	9 (10.98)	1 (1.96)	9 (14.06)	0 (0.00)		3 (11.54)
Prefer not to say	21 (15.56)	15 (18.29)	5 (9.80)	9 (14.06)	7 (11.29)		3 (11.54)
Ethnicity							
Hispanic or Latino	58 (43.94)	49 (60.49)	8 (16.33)	38 (61.29)	15 (24.59)		11 (44.00)
Not Hispanic or Latino	60 (45.45)	23 (28.40)	37 (75.51)	18 (29.03)	42 (68.85)		9 (36.00)
Unsure	4 (3.03)	4 (4.94)	0 (0.00)	3 (4.84)	1 (1.64)		4 (16.00)
Prefer not to say	10 (7.58)	5 (6.17)	4 (8.16)	3 (4.84)	3 (4.92)		1 (4.00)
Education level							
Less than high school	8 (5.88)	5 (6.10)	2 (3.85)			7th grade	1 (3.70)
Highschool graduate	31 (22.79)	30 (36.59)	1 (1.92)			8th grade	4 (14.81)
Some college	18 (13.24)	14 (17.07)	4 (7.69)			9th grade	4 (14.81)
2-year degree	8 (5.88)	4 (4.88)	4 (7.69)			10th grade	4 (14.81)
4-year degree	35 (25.74)	18 (21.95)	17 (32.69)			11th grade	6 (22.22)
Professional degree	26 (19.12)	5 (6.10)	21 (40.38)			12th grade	3 (11.11)
Doctorate	2 (1.47)	0 (0.00)	2 (3.85)			Highschool graduate	2 (7.41)
Unsure	2 (1.47)	2 (2.44)	0 (0.00)			Some college	2 (7.41)
Prefer not to say	6 (4.41)	4 (4.88)	1 (1.92)			4-year degree	1 (3.70)
Insurance Status							
Public insurance	63 (46.67)			39 (60.94)	19 (30.16)		
Private insurance	72 (53.33)			25 (39.06)	44 (69.84)		
Language spoken at home							
English	79 (58.09)	35 (42.68)	43 (83.69)	22 (33.85)	52 (83.87)		17 (62.96)
Spanish	29 (21.32)	26 (31.71)	2 (3.85)	24 (36.92)	2 (3.23)		3 (11.11)

(Continued)

Table 1. (Continued)

Demographic characteristics	All caretakers (n = 137)	Pediatric patient insurance status		Caretaker education level (years)		Demographic characteristics	All pediatric patients (n = 27)
		Public insurance (n = 83)	Private insurance (n = 52)	< 16 (n = 65)	16+ (n = 63)		
English and Spanish	9 (6.62)	8 (9.76)	1 (1.92)	7 (10.77)	2 (3.23)		4 (14.81)
Arabic	1 (0.74)	0 (0.00)	1 (1.92)	0 (0.00)	1 (1.61)		0 (0.00)
Other	17 (12.50)	12 (14.63)	5 (9.62)	11 (16.92)	5 (8.06)		3 (11.11)
Prefer not to say	1 (0.74)	1 (1.22)	0 (0.00)	1 (1.54)	0 (0.00)		0 (0.00)
Access to devices and Internet							
Use of desktop computer, laptop or tablet at home	110 (80.29)	58 (69.88)	51 (98.08)	43 (66.15)	62 (98.41)		26 (96.30)
Internet at home	131 (95.62)	78 (93.98)	51 (98.08)	60 (92.31)	63 (100.00)		27 (100)
Use of a smartphone	126 (92.65)	74 (90.24)	50 (96.15)	57 (87.69)	62 (100.00)		27 (100)
Annual household income							
\$0-\$29,999	31 (24.03)	27 (35.06)	4 (7.84)	25 (41.67)	5 (8.33)		
\$30,000-\$59,999	22 (17.05)	22 (28.57)	0 (0.00)	14 (23.33)	7 (11.67)		
\$60,000-\$89,999	11 (8.53)	6 (7.79)	5 (9.80)	6 (10.00)	5 (8.33)		
\$90,000	41 (31.78)	5 (6.49)	36 (70.59)	5 (8.33)	36 (60.00)		
Unsure	3 (2.33)	2 (2.60)	1 (1.96)	2 (3.33)	0 (0.00)		
Prefer not to say	21 (16.28)	15 (19.48)	5 (9.80)	8 (13.33)	7 (11.67)		
Patient's cardiac diagnosis							
Congenital Heart Disease	74 (55.64)	35 (44.30)	38 (73.08)	27 (44.26)	44 (69.84)		
Cardiac arrhythmia	14 (10.53)	8 (10.13)	5 (9.62)	7 (11.48)	7 (11.11)		
Unsure	45 (33.83)	36 (45.57)	9 (17.31)	27 (44.26)	12 (19.05)		
Patient's type of congenital heart defect							
VSD	21 (31.08)	10 (28.57)	13 (34.21)	7 (25.93)	15 (34.09)		
ASD	7 (9.46)	2 (5.71)	5 (13.16)	0 (0.00)	7 (15.91)		
AV canal defect	5 (6.76)	3 (8.57)	2 (5.26)	2 (7.41)	3 (6.82)		
Ventricular outflow tract obstruction	2 (2.70)	1 (2.86)	1 (2.63)	1 (3.70)	1 (2.27)		
Coarctation of aorta	7 (9.46)	3 (8.57)	4 (10.53)	0 (0.00)	7 (15.91)		
Vascular ring	2 (2.70)	1 (2.86)	1 (2.63)	2 (7.41)	0 (0.00)		
Tetralogy of Fallot	10 (13.51)	5 (14.29)	4 (10.53)	6 (22.22)	3 (6.82)		
TGA	8 (10.81)	3 (8.57)	5 (13.16)	2 (7.41)	6 (13.64)		
Single ventricle lesion	6 (8.11)	2 (5.71)	4 (10.53)	0 (0.00)	6 (13.64)		
Other CHD	32 (43.24)	17 (48.57)	15 (39.47)	11 (40.74)	20 (45.45)		
Patient reported time since diagnosis							
Days	3 (2.21)	2 (2.44)	1 (1.92)	2 (3.12)	1 (1.59)		
Months	22 (16.18)	19 (23.17)	3 (5.77)	17 (26.56)	4 (6.35)		
Years	99 (72.79)	52 (63.41)	45 (86.54)	37 (57.81)	54 (85.71)		
Unsure	12 (8.82)	9 (10.98)	3 (5.77)	8 (12.50)	4 (6.35)		
Patient's previous surgery for cardiac condition							
Yes	79 (58.09)	40 (48.78)	38 (73.08)	29 (45.31)	44 (69.84)		
No	56 (41.18)	41 (50.00)	14 (26.92)	34 (53.12)	19 (30.16)		
Unsure	1 (0.74)	1 (1.22)	0 (0.00)	1 (1.56)	0 (0.00)		

(Continued)

Table 1. (Continued)

Demographic characteristics	All caretakers (n = 137)	Pediatric patient insurance status		Caretaker education level (years)		Demographic characteristics	All pediatric patients (n = 27)
		Public insurance (n = 83)	Private insurance (n = 52)	< 16 (n = 65)	16+ (n = 63)		
Patient's hospitalization 2/2 cardiac condition							
Yes	52 (37.96)	38 (45.78)	14 (26.92)	24 (36.92)	24 (38.10)		
No	85 (62.04)	45 (54.22)	38 (73.08)	41 (63.08)	39 (61.90)		

VSD = ventricular septal defect, ASD = atrial septal defect, AV canal defect=atrioventricular canal defect, TGA = transposition of the great arteries, CHD = congenital heart defect.
^a Values represent number (%) of respondents unless otherwise indicated.

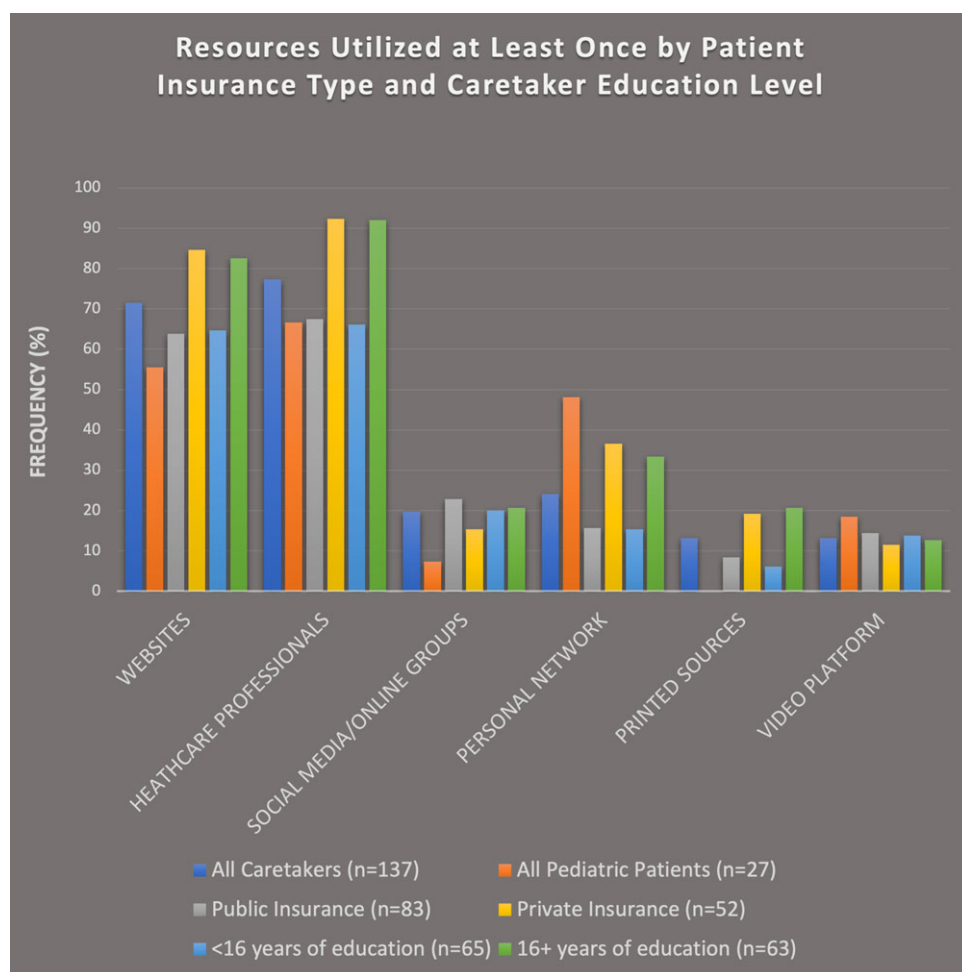


Figure 1. Caretakers' utilizations of websites, healthcare professionals, social media, personal contacts, printed sources, and videos to learn about paediatric cardiac conditions differed between groups stratified by education level and patients' insurance types.

[56%]). For patients who specifically indicated which healthcare professionals they consulted, 11/18 (61%) reported consulting someone other than their cardiologist to learn about the heart. The two most popular types of websites accessed by patients were commercial websites (7/11 [64%]) and hospital websites (5/11 [45%], Table 2, Fig. 1).

Resource utilization by paediatric patient insurance type

The frequency of caretakers who reported using websites, healthcare professionals, and someone from their personal

network was significantly different between groups stratified by the patient's medical insurance type. Caretakers of patients covered by private medical insurance more frequently reported using websites (44/52 [85%] versus 53/83 [64%], $p = 0.009$), consulting healthcare professionals (48/52 [92%] versus 56/83 [67%], $p = 0.008$), and utilising someone from their personal network (19/52 [36.54] versus 13/83 [16%], $p = 0.006$) to learn about their child's cardiac condition compared to caretakers of patients covered by public medical insurance (Table 2, Fig. 1). Although there were no significant differences in the proportion of caretakers who used commercial websites, government websites, hospital

Table 2. Resources utilization by patient insurance type and caretaker education level^a

Types of resources	All caretakers (n = 137)	All pediatric patients (n = 27)	Public insurance (n = 83)	Private insurance (n = 52)	Pearson's χ^2 p value	< 16 years of education (n = 65)	16+ years of education (n = 63)	Pearson's χ^2 p value
Websites	98/137 (71.53)	15/27 (55.56)	53/83 (63.86)	44/52 (84.62)	0.009	42/65 (64.62)	52/63 (82.54)	0.022
<i>commercial websites</i>	58/74 (78.38)	7/11 (63.64)	24/35 (68.57)	33/38 (86.84)	0.059	17/25 (68.00)	39/47 (82.98)	0.146
<i>government websites</i>	27/74 (36.49)	2/11 (18.18)	10/35 (28.57)	16/38 (42.11)	0.228	6/25 (24.00)	19/47 (40.43)	0.163
<i>hospital websites</i>	29/74 (39.19)	5/11 (45.45)	13/35 (37.14)	16/38 (42.11)	0.665	9/25 (36.00)	19/47 (40.43)	0.714
<i>peer-reviewed medical journal websites</i>	22/74 (29.73)	3/11 (27.27)	11/35 (31.43)	11/38 (28.95)	0.817	6/25 (24.00)	15/47 (31.91)	0.482
<i>national organization websites</i>	16/74 (21.62)	3/11 (27.27)	3/35 (8.57)	13/38 (34.21)	0.008	1/25 (4.00)	15/47 (31.91)	0.007
Healthcare professionals	106/137 (77.37)	18/27 (66.67)	56/83 (67.47)	48/52 (92.31)	0.001	43/65 (66.15)	58/63 (92.06)	< 0.001
<i>other</i>	55/98 (56.12)	11/18 (61.11)	23/51 (45.10)	31/45 (68.89)	0.019	21/40 (52.50)	33/53 (62.26)	0.345
<i>pediatric cardiologist</i>	96/98 (97.96)	18/18 (100.00)	49/51 (96.08)	45/45 (100.00)	0.497*	38/40 (95.00)	53/53 (100.00)	0.182*
Social media/online groups	27/137 (19.71)	2/27 (7.41)	19/83 (22.89)	8/52 (15.38)	0.289	13/65 (20.00)	13/63 (20.63)	0.929
Personal network	33/137 (24.09)	13/27 (48.15)	13/83 (15.66)	19/52 (36.54)	0.006	10/65 (15.38)	21/63 (33.33)	0.018
Printed resources	18/137 (13.14)	0/27 (0.00)	7/83 (8.43)	10/52 (19.23)	0.066	4/65 (6.15)	13/63 (20.63)	0.016
Video platform	18/137 (13.14)	5/27 (18.52)	12/83 (14.46)	6/52 (11.54)	0.627	9/65 (13.85)	8/63 (12.70)	0.848

^aValues represent number (%) of respondents unless otherwise indicated.

*Fischer's Exact test p value.

websites, and peer-reviewed medical journal websites, a larger proportion of caretakers with private medical insurance plans reported using websites of national organisations (such as healthychildren.org) compared to caretakers of patients covered by public medical insurance plans (13/38 [34%] versus 3/35 [8%], $p = 0.008$). Within the patient group, those covered by private insurance more frequently reported consulting their general paediatrician compared to those covered by public insurance (5/5 [100%] versus 2/10 [20%], $p = 0.007$).

Caretaker resource utilization by education level

Caretakers with higher education more frequently reported using websites (52/63 [83%] versus 42/65 [65%], $p = 0.022$), consulting healthcare professionals (58/63 [92%] versus 43/65 [66%], $p < 0.001$), utilising someone from their personal network (21/63 [33%] versus 10/65 [15%], $p = 0.018$), and using printed sources (13/63 [21%] versus 4/65 [6%], $p = 0.016$) to learn about their child's cardiac condition compared to caretakers with fewer than 16 years of education (Table 2, Fig. 1). There were no significant differences in the use of social media/online groups and video platforms among caretakers stratified by their level of education. Compared to caretakers with fewer than 16 years of education, a significantly higher percentage of caretakers with higher education indicated that the primary resource they used to learn about their child's cardiac diagnosis was healthcare professionals (38/62 [61%] versus 24/62 [39%], $p = 0.015$).

Access to devices and home internet by patient insurance status and caretaker education level

When comparing caretakers by insurance type, there were no significant differences in the proportion of caretakers with smartphones and Internet at home. A greater proportion of caretakers of patients covered by private medical insurance and those who completed higher education reported having access to a device, such as a desktop computer, laptop or tablet, when compared to caretakers of patients covered by public medical insurance (51/52 [98%] versus 58/83 [70%], $p < 0.001$) and those who completed fewer than 16 years of education (62/63 [98%] versus 43/65 [66%], $p < 0.001$), respectively (Fig. 2, Supplementary Table S2). Additionally, a significantly larger proportion of caretakers with higher education said that they use a smartphone compared to caretakers with fewer than 16 years of education (62/63 [100%] versus 57/65 [88%], $p = 0.006$). There were no significant differences in the proportion of caretakers who reported having Internet at home when stratified by educational attainment.

Caretaker satisfaction with resources

Mean caretaker satisfaction with the amount of information received about their child's cardiac condition (1 representing "extremely satisfied" and 5 representing "extremely dissatisfied") was 1.37 ± 0.63 . Mean patient satisfaction with the amount of information they received on their cardiac diagnosis was 1.44 ± 0.58 (Supplementary Table S3-S4). There were no significant differences in satisfaction with the amount of information received when caretakers were stratified by patients' insurance types. When asked "how often did the information you obtained agree with your doctors' recommendations?" (one representing "always" and five representing "never") caretakers averaged a score of 1.60 ± 0.75 and patients averaged a score of 1.56 ± 0.89 . There were no significant differences when comparing mean scores for

this question by caretakers' levels of education and by responders' medical insurance types. Additionally, when asked how often participants had access to information in their native language (one representing "always" and five representing "never"), caretakers averaged a score of 1.58 ± 1.12 , and patients averaged a score of 1.70 ± 1.20 . There was no significant difference in mean scores with regard to access to information in participants' native languages between caretakers who exclusively speak English at home and caretakers who speak at least one language other than English (such as Spanish or Arabic) at home.

Discussion

Disparities in health outcomes related to CHD continue to disproportionately affect vulnerable groups. Specifically, the incidence of CHD and risk of mortality in infants with CHD have been reported to be higher in ethnic minority groups living in areas of disadvantage characterised by factors such as poverty and low educational attainment.¹²⁻¹⁴ Recent studies have identified the importance of understanding how socio-economic factors relate to disparities in mortality and complications in children with CHD.¹⁵⁻¹⁸ Health literacy is a modifiable factor that mediates the relationship between social determinants and health disparities.^{19,20} However, there are limited data on how families learn about paediatric cardiac conditions and whether any differences in information seeking exist.

The results of this survey-based study demonstrated that websites and healthcare professionals (such as paediatric cardiologists, general paediatricians, and advanced care providers) are two of the most popular resources both caretakers and patients use to learn about paediatric cardiac conditions. Differences in the utilisation of resources to learn about the heart were identified when caretakers were stratified based on their levels of education and the type of medical insurance covering their children. There were fewer differences in the utilisation of social media, video platforms, and paediatric cardiologists as sources of information between groups. Since paediatric cardiologists were consulted most frequently among these resources (social media, video platforms, and health professionals), paediatric cardiologists should feel empowered to provide resources whenever possible to maximise patient and caretaker comprehension of paediatric cardiac conditions.

Notably, the level of education completed by caretakers participating in the study correlates with the utilisation of informative resources to learn more about paediatric cardiac conditions. Prior studies have reported that the average readability of online sources with material pertaining to cardiac conditions is above 6th-grade reading level.²¹ Not only does this potentially exclude caretakers with lower levels of education from engaging with these resources but it may also affect caretaker comprehension of online medical information thereby influencing caretakers' health-related decisions, compliance to therapies, and consequently paediatric patients' health outcomes.

Finally, grouping caretakers by their level of education revealed disparities in the utilisation of devices such as smartphones, laptops, desktop computers, and tablets. A lack of access to technology and low literacy with digital devices are barriers that exacerbate the "digital divide," or disparities in the utilisation of technology and technical knowledge.²² These disparities may contribute to differences in the accessibility and availability of resources families utilise to learn about the heart.²³ Despite no

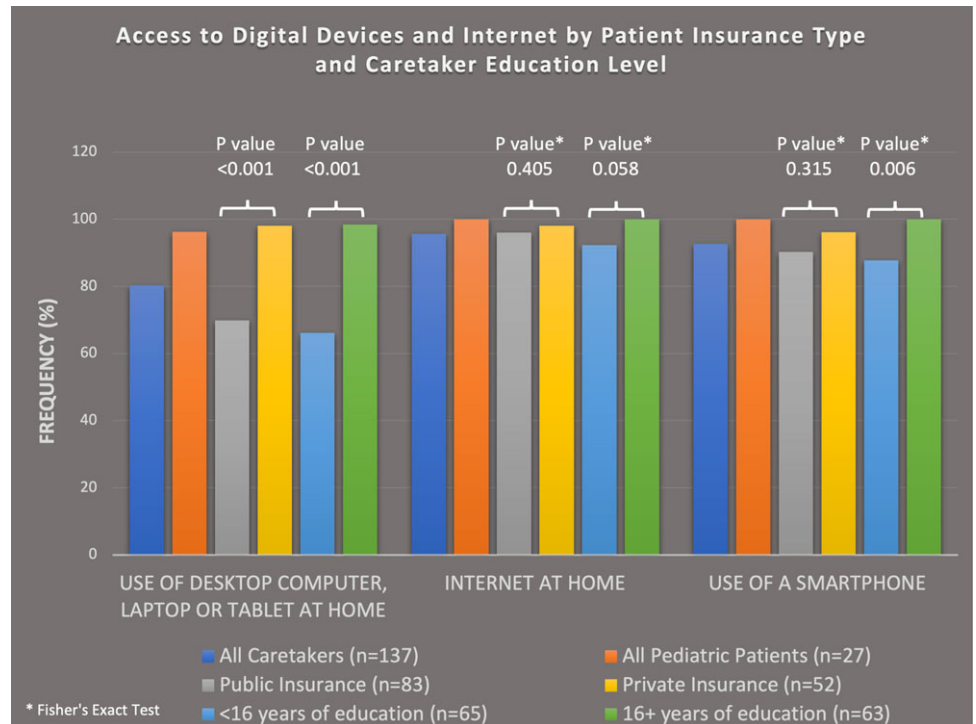


Figure 2. Caretakers differed significantly in their utilisation of devices such as smartphones and laptops when stratified by education level and patients' insurance types. There were no significant differences in access to the Internet between groups.

significant difference in how satisfied caretakers were with the amount of information they received, the digital divide that exists among caretakers of children with cardiac conditions highlights a potential need among low-income families for additional tools that serve to increase caretaker knowledge of the heart and caretaker engagement with information on paediatric cardiac conditions.²⁴

The study has several limitations. Given the small sample size of 27 paediatric patients, comparing patients' responses by insurance and caregiver education would likely have been insufficiently powered to detect significant differences. Additionally, while the survey was reviewed with several paediatric cardiologists at our institution, it was not piloted with a group of potential participants prior to implementation. Piloting the survey would have helped the research team identify survey questions that may be confusing or unclear to participants. Though study participants may have encountered ambiguities in the survey, a member of the research team was always available to help address any questions or concerns. The study was furthermore subject to biases. All eligible patients and caretakers were approached about the study when reasonably possible; however, completion of the study survey was potentially subject to selection bias since only those who consented and assented to participate in the study were provided with the study survey. Variations between participants with regard to cardiac history (such as the severity of the diagnosis, number of hospitalisations, and prior surgeries) raise the potential for recall bias, which may impact study results. Data on the total number of patients and caretakers who were eligible for participation or were approached about the study but did not start the survey was not collected; the 151 caretakers who took the survey is a subset of the total number of eligible participants. Finally, a significant limitation of this study is that all patients and caretakers included in the study were from a single centre. The processes through which medical information is provided to patients are often highly institution-specific; thus, this study is limited in its generalizability to other institutions.

In addition to bridging the digital divide and identifying new, widespread sources of information both within social media and video platforms, greater access does not guarantee the equitable distribution of reliable information, therefore, patients and their families may require more guidance on how to identify trustworthy sources.^{25,26} Further studies on how health literacy impacts health outcomes in children with CHD are needed to identify and target modifiable differences that may be leading to health disparities. Making sources of medical information low-cost, easily accessible (especially for families without stable resources such as devices, home internet, transportation, etc.), and available in different languages may be helpful for those with low health literacy. It is essential going forward that we identify issues surrounding access to sources of medical information and remove the barriers to access beleaguering populations affected by disinvestment. Additionally, there are limited data documenting how differences in the utilisation of informative resources affect health behaviour, decision-making, and health outcomes for children with CHD. Understanding whether variations in access to various digital and non-digital sources of medical information contribute to disparities in health outcomes is paramount in further identifying, which social determinants of health negatively impact children diagnosed with CHD.

Conclusion

Families of children with cardiac conditions vary significantly in the types of digital and non-digital resources they utilise and have access to for medical information. The use of websites, healthcare professionals, and personal contacts as sources of paediatric cardiac information varies significantly among caretakers when stratified by markers of socio-economic advantage and disadvantage such as caretakers' levels of education and types of medical insurance coverage. Identifying differences in information seeking may improve our understanding of how inequitable systems fail to

support families with low health literacy and further reinforce health disparities for children with CHD.

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Ethical standard. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation (the Belmont Report and the Federal Policy for the Protection of Human Subjects or “Common Rule”) and with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by the Institutional Review Board at Columbia University.

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