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Identification of research priorities in CHD: empowering patients and families through participation in the development of formal research agendas

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Abstract

Background: Conquering CHD, formerly known as the Pediatric Congenital Heart Association (PCHA), is the leading congenital heart disease (CHD) patient advocacy organisation in the United States of America, and places high priority on patient engagement in the research process. Participatory design is an approach to problem-solving that utilises the knowledge and opinions of groups of people to generate plans and new ideas. Utilising this mode of patient engagement, patients and families engaged with Conquering CHD assisted in developing a list of research priorities which was then distributed to the larger membership with instructions to rank the priorities in order of importance. Upon completion, these items were compared to the current scientific literature to assess correlation with current publications. This cross-sectional study and literature review aimed to assess the priorities of patients and families in CHD research and to determine the reflection of these areas in the current body of scientific literature. *Methods:* This cross-sectional study utilised a survey asking participants to rank the importance of research items within categories including "Technology Advances," "Genetic and Cellular Research," "Broad Understanding of CHD," and "Psychosocial Outcomes" which was distributed through social media and email to 43,168 accounts across all platforms. Respondents were asked to place each item in a ranked order in each category, with the value "1" representing the most preferred for each participant. Anyone engaged with Conquering CHD was eligible to complete the study, including patients and families. Subsequently, a literature review of the largest medical databases including PubMed, Scopus, and ScienceDirect was undertaken to determine the number of articles published per each topic which was then assessed to determine if there is a correlation between patient-ranked priorities and the current body of literature. *Results:* The study generated a total response of 527 participants. Regarding "Technology Advances," valve replacement was the preferred topic (mean rank 2.07, IQR 2). Stem cell research was the favoured topic in "Genetic and Cellular Research" (mean rank 2.53, IQR 2). Access to care was the priority in the "Broadening Understanding of CHD" (mean rank 1.24, IQR 1). Pertaining to "Psychosocial Outcomes", psychological/emotional effects was the highest ranked topic (mean rank 1.46, IQR 1). The literature review returned a total of 135,672 articles in the areas of interest. For "Valve Replacement", 8361 articles resulted reflecting a proportion of 0.097 of total articles. For "Stem Cell Research", 9921 articles resulted reflecting a proportion of 0.115 of total articles. For "Access to Care", 7845 articles resulted reflecting a proportion of 0.091 of total articles. For "Psychological/Emotional Effects", 6422 articles resulted reflecting a proportion of 0.074 of total articles. A Spearman's correlation demonstrated no correlation between the preferred domain of CHD research and the number of articles published for that domain ($rs = 0.02$, $p = 0.94$). *Conclusions:* This process demonstrates the effectiveness of participatory design, using a patient and family network to determine the research items of concern to those affected by CHD. The cross-sectional survey was effective in assessing patient and family priorities but was limited by access to reliable internet and delivery only in English. Though the study had a large response rate, it was limited to patients already engaged with Conquering CHD. For these reasons, it may not completely reflect the opinions of the total population affected by CHD. However, this offers valuable insight into patient-determined priorities and reveals that the current scientific literature does not correlate with these items. These data serve to inform individual and institutional research agendas to better reflect the needs and desires of this population.

Conquering CHD

Conquering CHD, formerly the Pediatric Congenital Heart Association, is a congenital heart disease (CHD) patient advocacy organisation in the United States of America. Conquering CHD exists to conquer the most common birth defect. This is accomplished through awareness, knowledge, community, and research. One of the pillars of this organisation is patient and family engagement. This tenet extends into research as well. Beginning in 2013, Conquering CHD has strived to involve the patient and family voice in decision-making and prioritising of advocacy resources. With this in mind, it was the aim of Conquering CHD to inform the landscape of research priorities important to patients and families through the development of a patient-driven research agenda.

Participatory design in healthcare

Participatory design is an approach to problem-solving that utilises the knowledge and opinions of groups of people to generate plans and new ideas. This method has proven particularly fruitful in industries that have enabled their employees to provide input on system-wide decisions.[1] Crowdsourcing, an approach within the realm of participatory design, describes the outsourcing of a problem or task to a community of individuals rather than to specific individuals.[2] The process of crowdsourcing can generally be described by three main components – identification of tasks, an online or open call for work, and a large group of distributed people.[3] Though healthcare is typically a patient- or family-centered delivery model, the use of this method of data and thought acquisition represents a powerful tool in the identification of patient- and family-centered research priorities.[2] This also offers the opportunity to engage with patients and empower them to shape the systems that affect their health.[4] Patient and family participation in such data mining may prove critical in shaping health policy and decisions.[2]

Crowdsourcing is becoming an increasingly popular tool in medical research. Several applications, including clinical and translational research, study recruitment, medication and genomic data, and community feedback and engagement have all demonstrated effectiveness.[5] This method offers a low-cost opportunity to collect massive amounts of data, but is not without its shortcomings, particularly generalizability to the general population.[5] However, this approach is not frequently utilised in paediatrics or CHD. This cross-sectional study and literature review aim to assess the priorities of patients and families in CHD research and to determine the reflection of these areas in the current body of scientific literature. In addition, this evaluation seeks to demonstrate the effectiveness and feasibility of crowdsourcing in CHD. It is anticipated that more patient-centered items including valve replacement, psychological/emotional effects, and access to care will score more favourably and likely will not reflect a correlation with current scientific literature.

Materials and methods

Survey design and distribution

After years of informal discussion, Conquering CHD planned a digital survey asking patients and families to rank the importance of specific types of research as it related to CHD in their lives. To generate the list of items included in the survey, Conquering CHD staff, volunteers, patients, and their families had informal discussions. These conversations blossomed into more robust discussions amongst the same populations and eventually garnered a preliminary list of research objectives. This was launched as an online survey, the "PCHA Research Priorities Poll" which contained an opening explanatory paragraph with definitions, five required questions, and six voluntary demographic questions. The survey took respondents an average of 7 minutes to complete.

The crowdsourcing tool was publicly released on September 6, 2019, and closed on October 1, 2019. During that time, the survey garnered 527 responses. Using Conquering CHD social media platforms on Facebook, Twitter, and Instagram, the digital survey targeted any individual with a patient or family connection to CHD. It is important to note that there was no age restriction on the tool and respondents may have included teenagers completing the survey on their own behalf. Posts included the survey link, QR code graphic, and a call to patients and families, which were shared on September 6, 2019, September 17, 2019, September 23, 2019, and September 30, 2019. The questionnaire was distributed through social media and email to 43,168 accounts across all platforms.

The tool was available only in English and asked participants to rank items within broader categories including "Technology Advances," "Genetic and Cellular Research," "Broad Understanding of CHD," and "Psychosocial Outcomes" in order of importance, with "1" representing the most preferred item. The items provided are as follows: in "Technology Advances", valve replacement, circulation assist devices, paediatric devices and pacemaker alternatives; in "Genetic and Cellular Research", stem cell research, tissue culture, predicting CHD, genome association screening, genome engineering, and animal models; in "Broad Understanding of CHD", access to care, long-term impact and early detection; in "Psychosocial Outcomes", psychological/emotional effects, neuropsychological issues, and access to medical records. In addition, the survey queried general demographic data, including relationship to CHD, age, level of education, income, and race/ethnicity. Anyone engaged with Conquering CHD was eligible to complete the study, including patients and families.

Statistical analysis

Data analysis was done with the R software.[6] Inferential analysis was done to compare the mean rank between options for each category of Technology; Genetic and Cellular Research; Broad Understanding of CHD; and Psychosocial Outcomes. Among each category, we compare the mean rank between the different options to help represent the magnitude of predilection among them. For this, we use Bayesian Multilevel random intercept ANOVA with the brms R package.[7] Bayesian inference allows to state direct inferences for the parameters of interest without needing a null hypothesis, and this is done by conditioning the model by the observed data.[8,9] Bayesian inference is described by a point estimate and the respective 95% credible interval. Multilevel modelling is applied to account for the same subject ranking all options within each category.[10] This model enables accounting for dependent responses, making direct inferences, and comparing the mean ranks between options.

Evaluation of correlation of priorities with current literature

The largest medical databases utilising Boolean search were identified including PubMed, Scopus, and ScienceDirect. These were queried for all articles in "congenital heart disease" alone over the past 5 years as of June 1, 2020. Then each database was queried for each identified research item using Boolean operators (i.e.

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(congenital heart disease) AND (valve replacement)) to generate the number of articles published under each topic. The relative percentage of total articles per topic was then obtained. Subsequently, Spearman's correlation was performed comparing the raw survey results to the number of articles obtained per topic to determine if there is concordance between priorities identified by crowdsourcing participants and the current body of literature on CHD.

Results

Demographic data of the survey participants are summarised in Table 1. The summarised rank of research items within each category is described in Table 2.

Regarding the mean rank comparison for "Technology Advances" preferences, pacemaker alternatives present the higher mean rank (M = 3.13, SD = 0.99), followed by paediatric devices (M = 2.57, SD = 0.89), circulation assistance devices (M = 2.22, SD = 1.12), and valve replacement (M = 2.07, SD = 1.14). When comparing the mean rank between circulation devices versus pacemaker alternatives, we find circulation being preferred with 95% confidence interval (M = 0.91, SE = 0.06, 95% CI = 0.79, 1.04). Similarly, when comparing circulation devices versus paediatric devices, the circulation devices are preferred with 95% confidence interval (M = 0.35, SE = 0.06, 95% CI = 0.22, 0.47). On the other hand, valve replacement was preferred over circulation devices with 95% confidence interval (M = −0.15, SE = 0.06, 95% CI = −0.28, −0.03). Comparing pacemaker alternatives with paediatric devices, we find that paediatric devices were preferred with 95% confidence interval (M = 0.57, SE = 0.06, 95% CI = 0.44, 0.69). Similarly valve replacement was preferred with 95% confidence interval over pacemaker alternatives (M = 1.06, SE = 0.06, 95% CI = 0.94, 1.19). Lastly, by comparing paediatric devices with valve replacement, valves were preferred with 95% confidence interval (M = 0.50, SE = 0.06, 95% CI = 0.38, 0.62).

In the area of "Genetic and Cellular Research," the topic with the lowest mean rank is stem cell research (M = 2.53, SD = 1.44), followed by tissue culture (M = 2.94, SD = 1.62), predicting CHD (M = 3.16, SD = 1.74), genome association screening (M = 3.35, SD = 1.44), genome engineering (M = 3.99, SD = 1.54), and animal models (M = 5.03, SD = 1.18). When comparing animal models with any other topic, we are 95% confident that any other topic is preferred. The mean rank differences are as follows: genome association screening (M = −1.68, SE = 0.09, 95% CI = −1.86, −1.49), genome engineering (M = −1.04, SE = 0.09, 95% CI = −1.22, −0.86), predicting CHD (M = −1.87, SE = 0.09, 95% CI = −2.05, −1.70), stem cell (M = −2.50, SE = 0.09, 95% CI = −2.69, −2.31), and tissue culture (M = −2.09, SE = 0.09, 95% CI = −2.28, −1.91). When comparing genome association screening, we are 95% confident that it has a lower mean rank than genome engineering (M = −0.64, SE = 0.09, 95% CI = −0.82, −0.46), and present a higher mean rank than the other topics: predicting CHD (M = 0.20, SE = 0.09, 95% CI = 0.02, 0.37), stem cell (M = 0.83, SE = 0.09, 95% CI = 0.64, 1.01), and tissue culture (M = 0.42, SE = 0.09, 95% CI = 0.23, 0.61). When comparing genome engineering with predicting CHD (M = 0.83, SE = 0.09, 95% CI = 0.66, 1.01), stem cell (M = 1.47, SE = 0.09, 95% CI = 1.28, 1.64), and with tissue culture (M = 1.06, SE = 0.09, 95% CI = 0.87, 1.24), we are 95% confident that genome engineering has a higher mean rank score than the other three topics. When comparing predicting CHD compared to stem cell (M = 0.63, SE = 0.09, 95% CI = 0.45, 0.81) and tissue culture (M = 0.22, SE = 0.09, 95% CI = 0.05, 0.4), we are 95% confident that predicting CHD has a higher mean rank. Lastly, comparing stem cell and tissue culture (M = 09.41, SE = 0.09, 95% CI = −0.59, −0.22) we are 95% confident that stem cell research has the lowest mean rank score.

The next area was "Broad Understanding of CHD," with the options to rank improvement of early detection (M = 1.94, SD = 0.86), long-term Impact of medications and treatments (M = 1.81, SD = 0.75), and access to care/health disparities (M = 2.24, SD = 0.77). Looking at the mean rank comparisons, between health disparities and improving early detection, we are 95% confident that health disparities is the less preferred topic (M = −0.30, SE = 0.05, 95% CI = −0.40, −0.21), the same

Table 1. Participant demographics and characteristics

	n (527)	Percentage of sample (%)
Relationship to CHD		
CHD parent	406	77.0
CHD patient	64	12.2
Extended family/friend	49	9.2
CHD sibling	5	0.9
Age of CHD patient		
Infant–3 Years	197	37.3
4–8 Years	102	19.4
9–12 Years	48	9.1
13–17 Years	62	11.8
18+ Years	82	15.6
Deceased	36	6.9
Highest level of education		
Masters or Higher	157	29.7
4 Year Degree	190	36.0
Some College/2 Year Degree	145	27.5
High School/GED	32	5.9
Household Income		
$150000+	74	14.0
$100000–$150000	116	22.0
$75000–$99999	100	19.0
$50000–$74999	111	21.0
$30000–$49999	69	13.0
$15000–$29999	37	7.0
Less than $15000	21	4.0
Race/Ethnicity		
Caucasian	417	79.1
Hispanic/Latino	52	9.7
Black/African American	17	3.2
Asian	16	3.1
Native American	13	2.5
Prefer Not to Answer	11	2.1
Pacific Islander	2	0.4

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Table 2. Mean rank comparisons by subcategory

Research area	Mean rank	Standard deviation
Technology advances		
Valve replacement	2.07	1.14
Circulation assistance devices	2.22	1.12
Pediatric devices	2.57	0.89
Pacemaker alternatives	3.13	0.99
Genetic and cellular research		
Stem cell research	2.53	1.44
Tissue culture	2.94	1.62
Predicting CHD	3.16	1.74
Genome association screening	3.35	1.44
Genome engineering	3.99	1.54
Animal models	5.03	1.18
Broad understanding of CHD		
Access to care	1.24	0.77
Long term impact	1.81	0.75
Early detection	1.94	0.86
Psychosocial outcomes		
Psychological/emotional effects	1.46	0.64
Neuropsychological issues	1.95	0.68
Access to medical records	2.58	0.69

conclusion shows when comparing health disparities with long-term impact, as health disparities is the less preferred topic ($M = -0.43$, $SE = 0.05$, 95% CI $= -0.52, -0.34$). Finally, when comparing improving early detection and long-term impact, long-term impact is the preferred topic, but for slight margin ($M = 0.13$, $SE = 0.05$, 95% CI $= 0.03, 0.22$).

The last area was "Psychosocial Outcomes," with psychological/emotional effects of CHD ($M = 1.46$, $SD = 0.64$), intervention for neuropsychological issues in CHD ($M = 1.95$, $SD = 0.68$), and benefits of patient access to medical records ($M = 2.59$, $SD = 0.69$). In the mean rank comparisons, we find that benefits of patient access to medical records is the least desired topic as we are 95% confident that intervention for neuropsychological issues in CHD has a lower rank mean ($M = -0.63$, $SE = 0.04$, 95% CI $= -0.72, -0.56$), as well as psychological/emotional effects of CHD have lower rank ($M = -1.13$, $SE = 0.04$, 95% CI $= -1.22, -1.05$). Lastly, when comparing Intervention for neuropsychological issues in CHD and psychological/emotional effects of CHD ($M = 0.5$, $SE = 0.04$, 95% CI $= 0.42, 0.58$), we are 95% confident that psychological/emotional effects of CHD is the preferred topic.

The raw data from the literature search are presented in Table 3 and aggregated in Table 4. "Query 1" for each entry was "congenital heart disease". A Spearman's correlation was used to assess the relationship between 'mean rank scores on patient/parent preferred domains of CHD research' and 'total number of articles published from years 2015 to 2020 on PubMed, SCOPUS, and ScienceDirect for that domain' using a sample of 528 participants. There was no correlation between the preferred domain of CHD research and the number of articles published for that domain, statistically not significant, $rs = 0.02$, $p = 0.94$.

Table 3. Research output by topic area

		PubMed		Scopus		Science Direct	
Query 2	Query 3	# Results	Proportion of Total Articles	# Results	Proportion of Total Articles	# Results	Proportion of Total Articles
Valve replacement		107	0.045	4837	0.078	3417	0.146
Assist device	Circulation assist	622	0.262	2081	0.034	2900	0.124
Pediatric device		142	0.060	5496	0.091	2600	0.111
Pacemaker		45	0.019	2611	0.043	2503	0.107
Stem cell		83	0.035	7124	0.117	2714	0.116
Tissue engineering		38	0.016	3849	0.063	1044	0.045
Genetic predictors	Genetic predisposition	78	0.033	4729	0.078	4779	0.203
Genome association	GWAS	17	0.007	5909	0.097	1730	0.074
Genome engineering	Genetic engineering	14	0.006	2430	0.040	689	0.029
Animal models		69	0.029	10258	0.169	4606	0.197
Access to care		35	0.015	3046	0.050	4764	0.203
Long term impact	Long term outcomes	154	0.065	18638	0.307	8896	0.380
Early detection		185	0.078	6460	0.106	4807	0.205
Psychological	Emotional	55	0.023	3859	0.064	2508	0.107
Neuropsychological		6	0.003	1081	0.018	344	0.015
Access to medical records		3	0.001	616	0.010	2694	0.115
	TOTAL	1653		83024		50995	

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Table 4. Aggregate research output across all databases

Query 2	Query 3	Aggregate # Results	Aggregate Proportion of total articles
Valve replacement		8361	0.097
Assist device	Circulation assist	5603	0.065
Pediatric device		8238	0.095
Pacemaker		5159	0.060
Stem cell		9921	0.115
Tissue engineering		4931	0.057
Genetic predictors	Genetic predisposition	9586	0.111
Genome association	GWAS	7656	0.089
Genome engineering	Genetic engineering	3133	0.036
Animal models		14933	0.173
Access to care		7845	0.091
Long term impact	Long term outcomes	27688	0.320
Early detection		11452	0.132
Psychological	Emotional	6422	0.074
Neuropsychological		1431	0.017
Access to medical records		3313	0.038
	TOTAL	135672	

Discussion

In this study, participatory design was applied in two stages – the generation of proposed research objectives and the critical evaluation and stratification of these areas of focus. This proved to be an effective model of data acquisition and evaluation but was not without its pitfalls. The demographic data of our respondents did not mirror that of the population affected by CHD, as the prevalence of CHD is roughly equivalent in all ethnicities in the United States of America.[11] This reflects a disparity between membership in Conquering CHD and participation in the survey among non-Caucasian patients and families. Further, as the survey was published only in English, this may also have limited respondents more comfortable in other languages. In addition, the response rate may also be limited in resource-poor areas, where lack of access to reliable internet service or devices would also present an obstacle. This study was also presented only to those already engaged with Conquering CHD, therefore limiting the sample to those interested in CHD advocacy and education, which may not necessarily reflect the general population affected by CHD.

In turn, this identifies an area of improvement in the recruitment and engagement of minority patients and families to benefit from the services, education, and support offered by Conquering CHD. Additionally, since the distribution of this survey, Conquering CHD is working to provide educational materials in both English and Spanish in order to offer more equitable engagement and information. This also speaks to the pervasive racial and ethnic disparities affecting paediatric healthcare.[12]

These data offer a stratified rank of the items of interest identified by the first focus groups. In this manner, the topics have been prioritised based on the preferences of affected patients and families. Dissemination of this data set enables clinicians and scientists to further target their own initiatives towards those that matter the most to patients. As researchers continue to pursue projects that support the health and well-being of patients and families affected by CHD, these formal objectives, identified by the individuals that their work supports, may offer valuable insight in the prioritisation of research agendas in laboratories, universities, and hospitals across the United States of America.

The Spearman's correlation fails to demonstrate a relationship between patient identified research priorities and current research output in CHD. This is to say that the current body of literature does not represent the research priorities of patients and families affected by CHD. However, this view is inherently biased by personal experiences and this survey does not necessarily reflect the views of the entire population affected by CHD. Further, the structure of the survey limited respondents to a predetermined listing of choices without the option to add areas of interest of importance to them. In addition, the methodology does not discern between quantitative and qualitative research which may have also considered patient priorities. With clinical and scientific advances, these identified areas of interest will certainly change. It is imperative to re-evaluate this association and continue to involve patients and families in the development of research agendas to integrate areas of importance of those affected by CHD in the research that will ultimately affect their lives.

This intervention offered a unique opportunity to engage with the membership of Conquering CHD to formally delineate research objectives supported by the broader organisation. This fosters a sense of commitment to the organisational objectives and allows each member to have a voice. It is in this manner that Conquering CHD strives to truly advocate for patient-centered research, beginning with the identification of investigation priorities.

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