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Adult congenital heart disease physical activity recommendation form: a feasibility study

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Abstract

Background: Adults with Congenital Heart Disease (ACHD) follow the same physical inactivity patterns as the general population. It is well known that physical inactivity is a risk factor for cardiovascular disease, and even more significant in the ACHD population. Health fears and misconceptions are common barriers to physical activity despite evidence supporting safety and efficacy of many activities for ACHD patients.

Methods: Feasibility Study with a convenience sample of 65 participants. The participants represented more moderate and complex diagnosis categorization. Participants completed the Stanford Brief Activity Survey (SBAS) and the Stanford Patient Education Research Questionnaire for Chronic Disease during enrollment. Participants received a Physical Activity Recommendation Form (PARF) with written instructions for utilization of the form at their next routine ACHD Provider clinic visit. Following use of the PARF, study participants completed a second SBAS and a PARF Utilization Satisfaction Survey, both returned in a pre-addressed envelope via regular mail to the investigators.

Results: Baseline data central tendency analysis determined 33% were not active, 43% were insufficiently active, and 24% were sufficiently active to obtain activity related health benefits. The majority of the lifestyle scores for all four indicators were in the (8–10 range) indicative of participant confidence in managing symptoms impacting activity of daily living. Much less confidence (3–5 range) in managing symptoms of fatigue, pain, and emotional distress. 80% of the PARF Utilization Surveys reported that use gave them more confidence in increasing activity level and less anxiety about exercise. 90% recommended PARF use for other ACHD patients. 50% reported an increase in physical activity following use of the PARF and study participation.

Conclusion: The ACHD Physical Activity Advocacy Study raised awareness and increased confidence in discussing physical activity with specialty ACHD healthcare providers for the ACHA study participants. Perceived benefit from the utilization of the PARF was paramount, but several interesting results related to activity and lifestyle were also demonstrated: only 24% were identified as sufficiently active and less than half expressed confidence in managing anxiety. Therefore, more research in this population is needed to better define the relationship between anxiety and activity levels to determine appropriate interventions for patient empowerment.

Trial registration: Trial registration, retrospective/pending, exempt low risk study per IRB approval and not indicated.

Keywords: Congenital heart defects, Physical activity, Physical activity recommendations, Adult congenital heart association, Anxiety, Empowerment

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Background

Regular physical activity participation is associated with a reduction in cardiovascular disease risk and improvements in physical and psychological health [2]. Adults with Congenital Heart Disease (ACHD) is the fastest growing population of survivors of childhood chronic illness with emerging morbidity that may be compounded by sedentary lifestyle [3, 4]. National recommendations from the American College of Sports Medicine [5] and the United States Department of Health and Human Services (DHHS): Moderate physical activity at least 30 min/day or 150 min/week with a minimum recommendation of 10–30 min daily summarized by the DHHS statement “Any activity is better than no activity.” [5, 6] Special chronic disease populations have even greater risks associated with sedentary lifestyle [2, 5].

The ACHD population follows the same physical inactivity patterns as the general population [2]. It is well known that physical inactivity is a risk factor for cardiovascular disease, including coronary artery disease with increased incidence of myocardial infarction (MI) [8]. An increased prevalence of MI in ACHD patients, greater than the general population, has been documented [7]. Health fears and misconceptions are common barriers to physical activity in ACHD, despite evidence supporting safety and efficacy of many activities [1]. The anxiety associated with these barriers prevent higher level daily activity above normal activities of daily living and light walking, especially in the ACHD population [8]. The desire for empowering patients to seek recommendations to boost confidence for increasing physical activity prompted a research study.

The purpose of the ACHD Physical Activity Advocacy Study was to empower patients to discuss individual physical activity recommendations with their ACHD specialist via the implementation of a Physical Activity Recommendation Form (PARF) [9] within 6 months of study enrollment. ACHA members often share fears regarding increase in regular physical activity and exercise during focused discussion groups. Some did not want to have an exercise stress test, and others expressed a lack of confidence to discuss or

ask questions during routine ACHD visits [10]. The study aimed to determine if utilization of the PARF was beneficial to ACHD patients and if motivation for increased physical activity and improved health achieved. Feasibility of posting access to the PARF for self-care and patient advocacy via central forum such as the Adult Congenital Heart Association website was also considered. The study focus was not on the implementation of the actual written daily activity recommendations, but the experience and perceived benefit of utilization of the PARF.

Methodology

The ACHD Physical Activity Advocacy Study was a collaborative project designed by two collegiate institution professors and the Adult Congenital Heart Association (ACHA) [10], a very active patient advocacy/support organization. Institutional Review Board approval was obtained and informed consent signed by all participants. Anonymity was maintained with de-identified study numbers on all pre/post questionnaires. The study investigators enrolled a convenience sample of 68 participants in attendance at the ACHA conference. Conference attendees visited the research room if they had interest in study participation. All participants were welcome and several bilingual patients participated and no interpreter services were needed. Three were disqualified due to incomplete SPERQ forms. In the end, data from 65 participants, 70% female was analyzed. Population demographics is displayed in Table 1. Participants were grouped per ACHD guidelines as simple, moderate, and complex diagnosis categorization as noted in Table 2. The descriptive study design was based on the following research questions.

Research questions posed

1. What is the self-reported physical activity level (ages 18–65) prior to a U.S. implementation of a Physical Activity Recommendation Form (PARF) [8]?

Table 1 Population Study Demographics. This table includes the age range, gender, marital status, educational status and ethnicity of study participants

	18–25	26–34	35–41	42–49	50>
	5	15	13	12	21
Gender	Male	Female			
	19	46			
Ethnicity	White	Black	Hispanic	Asian/Pacific	
	60	1	3	1	
Marital Status	Married	Single/Separated	Divorced		
	40	21/1	3		
Education level	High School	College	Graduate		
	2	36	27		

Table 2 Summary of congenital heart disease diagnoses represented in the study sample. This table includes all the congenital heart defects represented in the study

Simple <i>n</i> = 2	Moderate <i>n</i> = 31	Complex <i>N</i> = 29
Atrial septal defect	Tetralogy of Fallot	Single Ventricle
	Aortic Stenosis	Tricuspid Atresia
	Transposition of the Great Arteries	Double Outlet Right Ventricle
	Pulmonary Stenosis	Pulmonary Atresia

- Does the lack of a standardized PARF present a perceived barrier for ACHD specialists in providing activity advice?
- Does fear/anxiety about a congenital heart condition present a barrier to pursuit of physical activity?
- Does implementation of a PARF as a self-care advocacy tool empower ACHD patients to discuss and obtain written recommendations from their ACHD specialty providers?
- Does receipt of a completed PARF by their ACHD provider improve self-reported level of physical activity?

The study design included an enrollment baseline and post assessment phase as well as the active implementation of the PARF tool utilization at a routine clinic visit. Study participants were recruited on basis of anticipation of a routine ACHD clinic visit to be scheduled within the next 6 months and no special study-only appointments were to be scheduled as well as no virtual visits via fax or email of the PARF form to the providers for completion remotely.

Participants completed the Stanford Brief Activity Survey (SBAS) [11] Fig. 1, and the Stanford Patient Education Research Questionnaire for Chronic Disease (SPERC) [11] for baseline data in the initial enrollment phase. The SBAS focused on leisure and work physical activity, categorized into five levels of frequency and degrees of effort. The SPERC focused on confidence in managing symptoms during various activities of daily living as well as physical exercise.

The SBAS questionnaire classified leisure time physical activity into five categories (see Fig. 1):

- Most of my time sitting
- Light exercise on weekends
- Three times/week moderate activity 15–45 min
- Regular moderate/vigorous exercise 3 times/week for 30 min or more
- Moderate/vigorous exercise 30 min 5 days/week

Participants received a Physical Activity Recommendation Form (PARF) Fig. 2, with written instructions for

utilization of the form at their next routine ACHD Provider clinic visit. The PARF was the key tool, designed from a template shared by Dr. Graham Stuart (UK) [9] for this study, to empower ACHD patients to discuss physical activity recommendations with their ACHD specialty provider. The PARF form was modified from the UK adolescent focused template with minor change for adult focus following guidelines from American Heart Association and US Department of Health and Human Services for the US implementation. The PARF form was to be completed by the ACHD provider (MD, ARNP, PA) during visit with the copy given back to patient as a written reminder to enhance activity confidence with some recommendations. Following use of the PARF, study participants completed a second SBAS and a PARF Utilization Satisfaction Survey, both returned in a pre-addressed/postage paid envelope via regular mail to the investigators. Patients could mail the form from their home mailbox in the without need to walk or travel to a post office and thus very convenient and not a deterrent to the planned return of the two forms via regular mail. Electronic return of forms was considered but not utilized due to constraints with IRB approval.

Results

The study results effectively addressed all of the research questions and confirmed suspicion of a sedentary lifestyle of a large portion of ACHD patient sample, representative of the larger population. The baseline activity surveys provided activity data as well as lifestyle and quality of life as related to daily activity level (Table 3). The study sample was representative of the ACHD population and ACHA membership, which is reflected in the ACHA membership data: female 12,640 and male 5911, undeclared 2474. Thus, an expected increased number of female study participants, but noted a higher educational level than expected. Conference attendance alone and a desire to connect with other CHD peers is expected, but one might argue that higher educational level may be the impetus for this desire for ACHA membership and participation in such conferences and thus pose a demographic study bias.

Data analysis grouped activity levels as follows: (1) not active (2) insufficiently active (3) sufficiently active. Analysis of questionnaire data also categorized the 1–10 scored symptom management confidence into three groups: (1–4) low confidence (5–7) moderately confident (8–10) highly confident. Four additional questions were specifically analyzed to determine impact of symptoms and interference with activities of daily living and exercise. The analysis of the data was limited due to poor return rate of complete packets with the post study SBAS and satisfaction survey. Sixty eight of the eighty-two patients recruited completed enrollment and completion of all of the baseline data

Stanford Brief Activity Survey

Instructions This is a self-administer questionnaire that attempts to have the participants summarize his/her usual physical activity: **Section I** (on the job) and **Section II** (leisure-time) during the past year. Please read the entire questionnaire before answering. Select the answer that best represents your activity during the past year.

Please provide an answer for each statement: both your on- the- job and leisure- time activity. **If you are not gainfully employed outside the home...**but work regularly around the house, you should include this activity in the on- the- job section.

Section I: On-The-Job Activity

Please check the box next to the **one** statement that **best** describes the kinds of physical activity you usually performed while on the job this last year. If you are not gainfully employed outside the home but perform work around the home **regularly**, indicate that activity in this section

Section I		Section II	
<input type="checkbox"/> A	If you have no job or regular work, check Box A and go to Section II	<input type="checkbox"/> F	Most of my leisure time was spent without very much physical activity. I mostly did things like watching television, reading or playing cards. If I did anything else, it was likely to be light chores around the house or yard, or some easy-going game like bowling or catch. Only occasionally, no more than once or twice a month, did I do anything more vigorous, like jogging, playing tennis or active gardening.
<input type="checkbox"/> B	I spent most of the day sitting or standing. When I was at work I did such things as writing, typing, talking on the telephone, assembling small parts or operating a machine that takes very little exertion or strength. If I drove a car or truck while at work, I did not lift or carry anything for more than a few minutes each day.	<input type="checkbox"/> G	Weekdays, when I got home from work, I did few active things. But most weekend I was able to get outdoors for some light exercise- going for walks, playing a round of golf (without motorized carts), or doing some active chores around the house
<input type="checkbox"/> C	I spent most of the day walking or using my hands and arms in work that required moderate exertion. When I was at work I did such things as delivering mail, patrolling on guard duty, mechanical work on automobiles or other large machines, house painting or operating a machine that requires some moderate activity. If I drove a truck or lift, my job required me to lift and carry things frequently	<input type="checkbox"/> H	Three times per week, on the average, I engaged in some moderate activity- such as brisk walking or slow jogging, swimming or riding a bike for 15-20 minutes or more. Or I spent 45 minutes to an hour or more doing moderately difficult chores- such as raking or washing windows, mowing the lawn or vacuuming, or playing games such as doubles tennis or
<input type="checkbox"/> D	I spent most of the day lifting or carrying heavy objects or moving most of my body in some other way. When I was at work, I did such things as stacking cargo or inventory, handling parts or materials, or I did work like that of a carpenter who builds structures or a gardener who does most of the work without machines.	<input type="checkbox"/> I	During my leisure time over the past year, I engaged in a regular program of physical fitness involving some kind of heavy physical activity at least three times per week. Examples of heavy physical activity are: jogging, running or riding fast on a bicycle for 30 minutes or more; heavy gardening or other chores for an hour or more; active games or sports such as handball or tennis for an hour or more; or a regular program involving calisthenics and jogging or the equivalent for 30 minutes or more.
<input type="checkbox"/> E	I spent most of the day doing hard physical labor. When I was at work I did such things as digging or chopping with heavy tools, or carrying heavy loads (bricks, for example) to the place where they are to be used. If I drove a truck or operated equipment, my job also required me to do hard physical work most of the day with only short breaks.	<input type="checkbox"/> J	Over the past year I engaged in a regular program of physical fitness along the lines described in the last paragraph (I), but I did it almost daily- five or more times per week

Fig. 1 Stanford Brief Activity Survey. This survey was used to get base line leisure and occupational activity level of study participants

surveys. However, 12 patients returned the entire packet for analysis via mail of all post study components and 8 others sent back partial forms. Many other participants called or emailed with apology that they had lost their packet of forms or didn't think to take the PARF with them when they went for ACHD appointment.

Summarization of the key results from the data analyzed and depicted on these graphics, primarily confirmed suspicion of overall inactive or sedentary lifestyle. Baseline data analysis determined 33% of the study participants were not active, 43% were insufficiently active, and 24% were sufficiently active to obtain activity related health benefits. The majority of the SPERC scores for all four indicators were in the 8–10 range, indicative of

participant confidence in managing symptoms impacting activity of daily living. Lifestyle impact related to managing symptoms of fatigue, pain, and emotional distress, however, were reported with much less confidence in the 3–5 range. 80% of the respondents on the PARF Utilization Survey reported that use gave them more confidence in increasing activity level and less anxiety about exercise. 90% recommended PARF use for other ACHD patients. 50% reported an increase in physical activity following use of the PARF and study participation. The survey provided only a choice of yes or no with a space for comments in response to the questions, thus there is no information as to why only 50% increased their activity level, or how much they increased. One

***Study Form:** unauthorized duplication or general clinical use is prohibited by the investigators

(PARF-US) Adapted
with permission
from: Heart
research.uk (2014)

ACHD Physical Activity Recommendations Form

Name: Date:

Congenital Heart Defect :

Study PI Contact: Teresa Lyle DNP, ARNP, CPNP
Mobile#: (770) 289-7189
Email: tlyle@flsouthern.edu

Intensity of activity/exercise recommended		Check Appropriate Box(s)
Low intensity	Active, moving about, but no increase in HR or breathing i.e. home chores, walk/strolling, Tai Chi	<input type="checkbox"/>
Moderate intensity	Breathing harder but can still talk or sing i.e. Pilates, Yoga, light jogging, leisure biking, swimming, dancing	<input type="checkbox"/>
Vigorous intensity	Heart beats much faster - difficult to talk i.e. running, bike: spinning/mountain, Zumba, kickboxing	<input type="checkbox"/>
Amount of activity/exercise recommended		Check Appropriate Box
At least 30 mins per <u>day</u> ... OR ... 150 min per <u>week</u>	American College of Sports Medicine- Physical Activity Guidelines (2008)	<input type="checkbox"/>
10-30 minutes /day	"Any activity is better than no activity" Health & Human Services- Physical Activity Guidelines (2008)	<input type="checkbox"/>
Other :	Please specify:	
Types of activity/exercise to recommend		Circle as appropriate
Aerobic- (walking, swimming, running, jumping rope, racquet sports, etc.)	OK	AVOID
	Comment:	OTHER
Resistance- (Weight lifting with dumbbells/machine, stretch-bands, pull / push up body weight, etc.)	OK	AVOID
	Comment:	OTHER
Types of activity/exercise to avoid		Circle as appropriate
Activities with a high risk of impact (football, hockey, boxing, Martial arts)	OK	AVOID
	Comment:	OTHER
Activities with a high risk of cuts, scrapes and bruises (rock climbing, etc.)	OK	AVOID
	Comment:	OTHER
Competitive sport		Check appropriate box
Avoid all competitive sports (team sports leagues, masters swimming competitions, marathons, triathlons, bike races, etc.)	<input type="checkbox"/>	Comment:
May participate, but rest when necessary.	<input type="checkbox"/>	Comment:
May participate fully in all competitive sports.	<input type="checkbox"/>	Comment:
Exercise capacity considerations for vigorous activity/exercise/sports		
Peak Heart Rate (bpm) _____ Six-minute walk test (m) _____ VO2peak (ml/kg/min) _____		
Other:		
Additional Comments/Recommendations:		

Authorized by: _____ Valid until / Review date: _____ (Rev.8.5.14)

Fig. 2 Physical Activity Recommendation Form. This form was adapted from Dr. Graham Stuart's recommendation form and was given to study participants for their adult congenital cardiologist to complete at the participant's next clinic visit

person did comment that he/she was already meeting the recommended level of activity.

Discussion

Limitations in post PARF study data analysis was encountered due to several factors related to logistics with return mail and loss of the actual PARF following enrollment. An unanticipated ACHA office move & address change contributed to possible loss of returned surveys via mail. The variable time frame from enrollment in

study to ACHD provider visit in several cases was the suspected cause of loss of the PARF.

Although detailed but very simply step by step written instructions accompanied the PARF, several participants reported being confused about what to do with the PARF. Therefore, an additional limitation in the open-ended closure of study for follow through with the PARF &/or return of post surveys may have been impacted by participant's possible memory/executive function. Several patients that failed to return the full packet via mail called or emailed the investigator with apology and admission of losing the

Table 3 Baseline activity data summarized from the enrollment questionnaires. This table summarizes the baseline activity data from the Stanford brief activity survey and the Stanford Patient Education Research Questionnaire for Chronic Disease

Baseline Activity Data	
33%	Not Active
43%	Insufficiently Active
24%	Sufficiently Active to attain health benefits
Lifestyle Indicators	
80%	Reported use of PARF gave more confidence and less anxiety about being active / exercise
90%	Recommended PARF for others to use with ACHD visit/ discussion with providers
50%	Stated they increased their level of physical activity after use of the PARF
42%	Expressed confidence in managing anxiety

forms and / or failing to remember to take them to their appointment. Some had routine appointments planned or scheduled within 3–6 months following enrollment, which was an inclusion criterion for participation. This omission of follow through was not perceived as a failure to engage, but an issue of the variable time interval and possibly result of being without interim reminder communication. Neuro-cognitive issues have been known to occur in the ACHD population especially with regard to executive function [12, 13].

In addition, this convenience sample was representative of conference attendee and of members of the ACAH, a majority female. The ACHA currently does not collect data on ethnicity, race, marital status or education, therefore no conclusions can be drawn about the representation of the sample size.

Conclusion

The Physical Activity Recommendation Form Feasibility Study raised awareness and increased confidence in discussing physical activity with providers for ACHA patient participants. Feasibility of use of the PARF was confirmed and felt to be beneficial by patients and providers. Baseline data analysis from the Stanford Activity Surveys revealed that ACHD survivors were not sufficiently active to attain health benefits, even with household and leisure activity included and activity not just defined as physical exercise. Additional research to improve confidence and increased physical activity in ACHD patients is needed. Further study would afford opportunity to evaluate not only increased motivation but the impact of PARF utilization on the actual increase in activity level with a tool to measure compliance. Possible next steps would be to have a PARF available on the ACHA website as a tool that could be downloaded by members and ACHD providers for

utilization during routine specialty follow up visits. ACHD provider recommendations to facilitate healthy physical activity vs. formalized exercise prescriptions that may require special diagnostic testing, to be considered for inclusion in next revision of the ACHD Management Guidelines [14]. Feasibility of PARF use and subsequent benefit to the ACHD patient population was demonstrated in this study. Empowerment of both the patients and providers with the ease of access/availability of a tool such as the PARF is needed to facilitate improvement in future physical activity and overall health outcomes.

Abbreviations

ACHA: Adult Congenital Heart Association; ACHD: Adults with Congenital Heart Disease; DHHS: Department of Health and Human Services; MI: Myocardial Infarction; PARF: Physical Activity Recommendation Form; SBAS: Stanford Brief Activity Survey; SPERC: Stanford Patient Education Research Questionnaire for Chronic Disease; UK: United Kingdom

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Availability of data and materials

Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

Authors' contributions

Study design/implementation (50/50) IRB/Manuscript writing (80/20 Lyle/Hartman). All authors read and approved the final manuscript.

Ethics approval and consent to participate

The study received Institutional Review Board Approval from Florida Southern College, The University of North Florida, and the Research Committee at the Adult Congenital Heart Association. Informed consent was obtained from all participants and anonymity maintained with de-identification of all surveys in the study binder.

Consent for publication

Our manuscript contains no individual personal data.

Competing interests

The authors declare they have no competing interests.

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