Are Grown-ups with Congenital Heart Disease Willing to Participate in an Exercise Program?

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ABSTRACT

Objective. To examine the willingness of grown-ups with congenital heart disease (GUCH) to participate in the GUCH Training Program-Individualised (GTI), an exercise program specifically designed for GUCH, and to identify factors affecting their willingness to participate.

Design and Setting. In this cross-sectional study, all outpatient GUCH of the University Medical Center Groningen in The Netherlands, living within a 30-km radius of Groningen (n = 311), were asked to participate.

Patients. In total, 116 (37%) of the 311 GUCH who are invited to participate in our study returned completed questionnaires. The median age of the respondents was 40 (interquartile range 31–50) years and 55% were women.

Outcome Measures. Respondents (n = 116) completed a questionnaire that queried physical activity, perceived physical fitness, psychosocial determinants (motivation, self-efficacy, and social support) related to physical activity, and willingness to participate in GTI.

Results. Of the 116 respondents, 68 (59%) were willing to participate in GTI. They were less physically active, had worse perceived physical fitness, were less satisfied with their fitness, were generally more motivated to engage in physical activity, and had more social support than patients unwilling to participate. The best logistic regression model predicting willingness to participate in GTI included the variables perceived physical fitness and motivation for physical activity in general.

Conclusions. Asking GUCH to participate in an exercise program supervised by physical therapists is a good strategy. Taken into account nonresponse, a participation rate in the exercise program of over 20% is to be expected. Perceived physical fitness and motivation for physical activity in general are important predictors of patients’ willingness to participate.

Key Words. Exercise; Congenital Heart Disease; Physical Activity; Perceived Fitness; Motivation

Introduction

The population of grown-ups with congenital heart disease (GUCH) continues to grow.¹,² Nowadays, the focus of cardiac medical care has shifted from survival to terms of quality of life.³–⁵ Exercise capacity is central to quality of life but is often reduced in GUCH.⁶–⁹ Reduced exercise capacity can be caused by not only cardiopulmonary problems,⁸ overprotection, or fear¹⁰–¹² but also by a sedentary lifestyle.⁸,¹³,¹⁴ Hence, GUCH should be encouraged to be physically active, including exercise training and sports,²,⁸,¹⁵ because doing so can improve their exercise capacity.⁶,⁸,¹⁶ Furthermore, enhanced physical activity can improve self-esteem and can positively affect cardiovascular, musculoskeletal, and functional status. Together, this will result in an improved quality of life.¹⁵ Physical activity and exercise training is safe for the majority of cardiac pathologies in GUCH.⁶,¹⁴,¹⁷

An exercise program called the GUCH Training Program-Individualised (GTI) has been developed to increase exercise capacity, with the aim of improving quality of life. Although previous research suggests that most GUCH are interested in exercise and appropriate advice,¹⁰,¹⁸ it is unknown whether GUCH are willing to par-
participate in exercise programs. Multiple factors might contribute to their “willingness,” which is defined as the actual commitment to participate in GTI. For example, demographic, clinical, or psychosocial factors, current physical activity level, or perceived physical fitness may play a role.

The objective of this study was to examine the willingness of GUCH to participate in an individualized exercise program (GTI) intended to improve their exercise capacity. The second objective was to identify factors that predict their willingness. The effects of GTI will be evaluated in a future study.

Methods

Study Sample and Design
In this cross-sectional study, all outpatient GUCH of the University Medical Centre Groningen in the Netherlands, living within a 30-km radius of Groningen (n = 311), were asked to participate. The study complied with principles outlined in the Declaration of Helsinki and was approved by the local ethics committee. All participants gave their informed consent.

Data Collection
All 311 patients received a physical activity questionnaire (Godin Leisure Time Questionnaire19) and a short questionnaire we developed—partly based on the Theory of Planned Behavior—to gather information on demographic characteristics, perceived physical fitness, psychosocial determinants related to physical activity (motivation, self-efficacy, and positive and negative social support), and willingness to participate in an exercise program. Respondents not willing to participate in GTI were labeled “GTI-no”; those willing to participate were labeled “GTI-yes.” Disease-specific characteristics were derived from respondents’ medical records.

Data Analyses
Descriptive statistics were used to examine respondents’ characteristics and willingness to participate in GTI. Mann–Whitney U-tests (two sided) and chi-square tests (two sided) were conducted to examine differences between “GTI-yes” and “GTI-no.” Logistic regression analyses (method backward: likelihood ratio [LR]) were used to identify variables that predicted willingness to participate in GTI. All analyses were performed with SPSS (SPSS Statistics for Windows, Version 17.0. Chicago, IL, USA); P < .05 was considered statistically significant.

Results

Study Sample
In total, 116 (37%) of the 311 GUCH who are invited to participate in our study returned completed questionnaires. Characteristics of the study sample are presented in Table 1.

Willingness to Participate in an Exercise Program
Of the 116 respondents, 93 (80%) were interested in improving their physical fitness and 23 (20%) were not. The main reasons for not being interested were satisfied with current physical fitness (43%) and lack of time (38%). Patients could be interested in improving their physical fitness but not willing to participate in GTI. In total, 68 respondents (59%) were willing to participate in GTI (“GTI-yes”) and 48 (41%) were not (“GTI-no”) (Figure 1).

Determinants of Willingness to Participate in GTI
GTI-no patients were more physically active, had better perceived physical fitness, were more satisfied with their fitness level, were less motivated to be(come) physically active in general, and perceived less social support than GTI-yes patients (Table 1). There were no significant differences in other characteristics (Table 1).

To determine which determinants predict willingness to participate in GTI, logistic regression analyses were performed (method backward: LR) with the variables moderate-vigorous physical activity, perceived physical fitness, satisfaction with physical fitness, motivation for physical activity in general, and positive social support entered as independent variables. The best model included perceived physical fitness and motivation for physical activity in general:

\[ \text{Predicted logit of willingness to participate in GTI} = -3.652 + (-1.095 \times \text{perceived physical fitness}) + (1.785 \times \text{motivation for physical activity in general}) \]

According to the model, the log odds of a patient willing to participate in GTI was negatively related to perceived physical fitness (P < .001) and positively related to motivation toward physical activity in general (P < .001) (Table 2). This model correctly predicted 81.1% of all cases, was significantly better than the null model, and fit the data well (Table 2).
Discussion and Conclusion

Previous research has indicated that most GUCH are interested in exercise and appropriate physical activity advice. However, the present study is the first study to examine their willingness to participate in an individualized tailor-made exercise program (GTI) and to identify factors that predict willingness to participate. It can be concluded that 59% of the respondents were willing to participate.
in GTI to improve exercise capacity. Their perceived physical fitness and motivation in relation to physical activity in general were the most important predictors of willingness to participate.

The main reason GUCH were not interested in improving their physical fitness was that they were satisfied with their physical fitness (43%). This was followed by a lack of time (38%) and

**Figure 1.** Flowchart: visual presentation of the response rate and the number of patients willing and not willing to participate in GTI. GTI, GUCH Training Program-Individualised; GUCH, grown-ups with congenital heart disease.

**Table 2.** Logistic Regression Analysis Predicting Willingness to Participate in GTI

<table>
<thead>
<tr>
<th>Predictor</th>
<th>B</th>
<th>SE B</th>
<th>Wald’s $\chi^2$</th>
<th>df</th>
<th>$P$</th>
<th>$\theta$ (Odds Ratio)</th>
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<tbody>
<tr>
<td>Constant</td>
<td>-3.652</td>
<td>2.230</td>
<td>2.680</td>
<td>1</td>
<td>.102</td>
<td>.026</td>
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<tr>
<td>Perceived physical fitness</td>
<td>-1.095</td>
<td>.269</td>
<td>16.616</td>
<td>1</td>
<td>.000</td>
<td>.334</td>
</tr>
<tr>
<td>Motivation</td>
<td>1.785</td>
<td>.431</td>
<td>17.150</td>
<td>1</td>
<td>.000</td>
<td>5.960</td>
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</table>

<table>
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<th>Test</th>
<th>$\chi^2$</th>
<th>df</th>
<th>$P$</th>
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<tr>
<td>Overall model evaluation</td>
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<td>.000</td>
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<td>Likelihood ratio test</td>
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<tr>
<td>Goodness-of-fit test</td>
<td>3.995</td>
<td>8</td>
<td>.868</td>
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</tbody>
</table>

df, degree of freedom; GTI, GUCH Training Program-Individualised; SE, standard error.
disease-related symptoms (19%). This is little different than the findings of another study, which concluded that disease-related symptoms (32%), followed by lack of interest in exercise (24%), were the most important barriers to exercise for GUCH. Only 5% of their participants listed “satisfaction with their current physical fitness” as a reason not to exercise. This apparent discrepancy with our findings might be due to the difference between willingness to exercise and willingness to improve physical fitness. The median score on perceived physical fitness of the participants in the present study was 6.0 (interquartile range 5.0–7.0) on a scale from 0 to 10. Other research showed that perceived physical fitness only poorly relates to actual physical fitness. It should be noted that GUCH tend to overestimate their physical capacity.

Patients willing to participate in GTI were less physically active, had lower perceived physical fitness, and were less satisfied with their fitness level than patients not willing to participate. This suggests that we succeeded in including patients in GTI for who GTI was originally developed. Strikingly, there were no significant differences in the demographics (e.g., age and distance to training center) and disease-specific characteristics (e.g., disease severity) of GTI-yes and GTI-no patients. Another recent study reported as well that young adults with congenital heart disease are interested to participate in an exercise program, regardless of long travel or other organizational difficulties.

The present study showed that the higher a patient perceived his/her physical fitness, the less likely the patients was willing to participate. If a patient was more motivated to engage in physical activity in general, he/she was more likely to participate in GTI. By assessing the willingness of GUCH to participate in an exercise program, we only assessed the intention to participate in an exercise program and not actual participation. However, according to the Theory of Planned Behavior, intention to perform a specific behavior is the best predictor of actual performing that behavior.

Whether the patients who were willing to participate would actual participate in the exercise program, should further research reveal.

Our results indicate that the majority of responding GUCH had a sedentary lifestyle. Only 17% of the respondents met the physical activity recommendation of at least 30 minutes per day of moderate to vigorous physical activity for most days of the week. Our findings are comparable with those of another study, which found that only 14% of GUCH met the recommended physical activity level.

Similar results were found by Buys et al. who reported that only 19% of the GUCH participating in their study (n = 103) had a vigorously active lifestyle. However, another study found a much higher percentage of patients meeting the recommended level of physical activity (76%). More research is needed for an accurate view of physical activity levels in GUCH, but several studies showed that GUCH are less physically active than healthy adults. Furthermore, our results show that 50% of GUCH suffer from overweight or obesity, which is comparable with the healthy population. Due to this unhealthy behavior (overweight and sedentariness), GUCH have additional health risks. Therefore, it is important to promote in them a healthy lifestyle that includes physical activity and exercise. Because 59% of responding GUCH were willing to participate in GTI and taken into account number of nonrespondents, it would be worthwhile to examine whether other strategies promoting physical activity might attract more GUCH.

Some study characteristics should be taken into account when interpreting our results. The response rate was low (37%), which could have caused selection bias. Furthermore, physical activity and fitness were measured with a self-report questionnaire. Grown-ups with congenital heart disease are likely to overestimate their physical functioning. However, the way patients perceive themselves importantly reflects their quality of life or well-being and provides valuable information. Although the short questionnaire to measure psychosocial determinants was based on the Theory of Planned Behavior, for future research we recommend using questionnaires that have proven reliability and validity in the GUCH population.

In conclusion, overweight and sedentariness are highly prevalent in GUCH. Therefore, it is important to promote an active healthy lifestyle. Fifty-nine percent of our respondents were willing to participate in an exercise program. This illustrates that asking GUCH to participate in an exercise program supervised by physical therapists is a good strategy. Taken into account nonresponse, a participation rate in the exercise program of over 20% is to be expected. Perceived physical fitness and motivation to be physically active in general were the most important predictors of willingness to participate. Other factors such as age, level of education, distance to the training center, and disease severity were not related to willingness to participate in an exercise program.
which indicates that it is worthwhile to approach a wide range of patients for such an exercise program.

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Author Contributions

MLD designed and executed the statistical analyses and wrote the first draft of the article. MF was involved in data collection and reviewed and critiqued the article. MHGdG reviewed and critiqued the statistical analyses and the article. WN and ESH conceived and organized the research project and reviewed and critiqued the article. All authors read and approved the final article.

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