



Discussion

Response to Comment on the original paper entitled “Can a home-based cardiac physical activity program improve and sustain quality of life and exercise capacity in children with Fontan circulation?”



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We would like to thank the commentator for their thoughtful critique of our study investigating the 6-month follow-up outcomes in Fontan patients after completion of a 12-week physical activity program. We acknowledge the points made regarding our study limitations and would like to provide some additional information and comments to clarify a few of the points that were addressed.

During the 12-week physical activity program, study participants attended 3 in-person sessions, which parents and siblings were encouraged to attend. At those sessions, 2 participants would complete the PACER test side-by-side in front of the other study participants and families, which often resulted in a friendly competition. The other study participants and families would encourage and cheer for those doing the PACER test. Thus, it is very feasible that a positive social interaction among the study participants during the 12-week program may have influenced the results of the study, in particular the measures of HRQOL, beyond the exercise program itself. The study participants were allowed to keep their activity monitors after the 12-week program, which provided the opportunity for them to continue to communicate with and compare their physical activity level to other study participants via the secure online community. Unfortunately, we did not specifically inquire about the nature and frequency of contact among the original study participants and their families during the 6-month follow-up period. Anecdotally, there were several patients that did keep in contact regularly, but we did not systematically collect this data.

As we mentioned in the original publication, all the study participants received an activity monitor. Based on this objective data, there

were marked improvements in the average number of steps of the participants during the study period, indicating an increase in physical activity. Although the study participants were allowed to keep their activity monitors during the 6-month follow-up period, there was a decline in the number of participants reporting their physical activity data on a regular basis. Thus, we do not have accurate data available regarding the number of study participants who continued their physical training after the 12-week program. However, as we move forward with further studies, this is data we plan to monitor.

The cardiologist has a critical role to initiate the conversation with patients about the importance and safety of regular physical activity. Knowledge about the safety of physical activity is often the major barrier to increasing activity levels in children and adolescents with complex congenital heart disease, and thus, addressing this concern will open up the potential for patients to be more active. However, we agree that a formal physical activity program requires more than a provider to monitor the safety of the program. It requires a multidisciplinary team that incorporates some combination of a psychologist, physical and occupational therapist, and exercise physiologist. In addition, given emerging data about the role of pulmonary limitation to physical activity in Fontan patients, it would be reasonable to include a specialist in pulmonary rehabilitation as well.

Conflict of interest

There are no conflicts of interest for any of the authors.

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<https://doi.org/10.1016/j.ppedcard.2018.11.006>

Received 26 November 2018; Accepted 26 November 2018

Available online 11 January 2019

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