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Being physically active as an adult with congenital heart disease

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Abstract

Background: Due to advances in medical and surgical care adults with congenital heart disease (CHD) is a growing and aging population, that now outnumbers the children with CHD. In general, adults with CHD have reduced aerobic exercise capacity and nearly half of the patients do not reach current recommendations on physical activity. It is known that a low level of physical activity is associated with an increased risk for acquired cardiovascular disease. Studies has shown that adults with CHD are at the same, or even higher risk as the general population, for developing acquired cardiovascular disease.

Aim: The overall aim was to explore physical activity in adults with CHD with respect to associated factors, exercise self-efficacy and their own experiences.

Methods: This thesis is based on four papers. Paper I included 471 adults with CHD from three tertiary care centres in Sweden. The participants completed questionnaires measuring patient reported outcomes (e.g. SF-12) including physical activity level. Paper II was based on data from 79 adults with CHD from two tertiary care centers in Sweden and 42 matched controls. All participants completed questionnaires on exercise self-efficacy and quality of life, wore an activity monitor during four consecutive days and performed muscle endurance tests. Paper I and II were of cross-sectional design and analyses were done using logistic regression. In paper III and IV data were collected through structured interviews for 14 participants. They were asked about their experiences of being physically active (paper III), what they considered as physical activities, and their experiences of enablers and barriers to physical activity (paper IV). Qualitative content analysis was used in papers III and IV.

Results: Physical activity level (paper I) and exercise self-efficacy (paper II) were strongly associated with age where those over 40 years had a lower level of physical activity and lower exercise self-efficacy. Further, in paper I, it appeared that patient reported outcomes from SF-12 were strongly associated with physical activity level. In paper II, exercise self-efficacy was associated with performance in a muscle endurance tests.

Paper III revealed an overall theme – It’s like balancing on a slackline that illustrates how adults with CHD described themselves in relation to physical activity. This overall theme consisted of four themes: (1) Being an adventurer – enjoying the challenges of physical activity; (2) Being a realist – adapting to physical ability; (3) Being a non-doer – lacking prerequisites for physical activity and (4) Being an outsider – feeling excluded depending on physical ability. In paper IV, the analysis revealed a description of what adults with CHD consider to be physical activity and considered as enablers and barriers for physical activity. Four categories appeared; physical aspects, psychological aspects, psychosocial aspects and environmental aspects. In the psychosocial aspect, social support and encouragement in childhood to be physically active and no restrictions from e.g. parents, teachers and health care increased physical activity in adulthood.

Conclusions: Age, social support and accepting physical limitations seem to have an important impact regarding physical activity level and exercise self-efficacy. In contrast, the complexity of CHD and other medical factors appear to be of less importance for adults with CHD in relation to physical activity. In order to support adults with CHD to increase their physical activity and reach their full potential, it is important to explore and consider the various aspects that may affect physical activity in this population.

Keywords

Adult congenital heart disease, congenital heart disease, heart defect, physical activity, exercise self-efficacy, muscle function, quality of life, nursing, interviews, content analysis, prevention

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