

What about life experiences of Congenital Heart Disease adolescents' parents? A literature review and meta-synthesis

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Introduction

Congenital Heart Diseases (CHD) do not preclude the possibility to become adult due to the different innovations in medical and surgical treatments. The transition from childhood to adulthood is a complex process in the lives of all young people, and it is particularly important for CHD adolescents, considering the consequences of their diseases and the need to be adherent with their follow-up indications. In this process, parents play an important role, being a landmark for their children. For this reason, the knowledge of their experiences is important to address a tailored and efficient health-care delivery for the whole family. However, the current scientific literature is mainly focused on quality of life of CHD patients, while the experiences of CHD adolescents' parents are less studied and the literature about their life experiences appears fragmented. Therefore, the aim of this study is to synthesize qualitative papers of life experience of CHD adolescents' parents.

Methods

A review of the literature was performed, considering as main topic the CHD adolescents' parents experiences through a literature search in the last 20 years, in accordance with the PRISMA guidelines and PICO's method. Databases searched included PubMed, CINAHL, PsycINFO and Google Scholar and keywords used are "Congenital heart disease", "Parents", "Adolescents" and "life experience". Only the qualitative papers were included.

Results

The search yielded 405 potentially relevant studies for screening, and only 7 articles met all the inclusion criteria. These papers were analyzed, discussed and a qualitative meta-synthesis was performed, according to the Noblit & Hare methodology. The meta-synthesis results were 4 main themes, exploring 4 main contradictions that characterize the CHD adolescents' parents experiences: "fear and uncertainty of the future versus positive coping strategies"; "parents hyper-responsibility and overprotection versus adolescents' independence desire"; "desire to give support, but not to be supported"; "normality desire versus awareness to live with particular conditions".

Conclusions

The role of the CHD adolescents' parents is difficult and they experience some contradictions. This study explore their life experiences in an preliminary way, but further analysis and studies are needed.