

How could the clinicians assess the CHD adolescents' and their parents' needs? A preliminary theoretical basis underpinning a tool development

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Introduction: Literature currently shows a growing interest in understanding the peculiarities of both the patients with congenital heart disease (CHD) and their parents, whom are living the transition period from childhood to the adulthood, known as adolescents. However, considering the parents' crucial role and some risky behaviors related to their duties (e.g., hyper- protection, fear), there are not yet available tools to specifically assess the needs of both the adolescent patients and their parents. Therefore, it could be strategic the identification of a clear theoretical framework that could guide a CHD-specific tool development to assess their needs. Thus, the aim of this study is to identify a theoretical framework, which will guide a future tool development.

Methods: The theoretical framework will be defined by a literature review (phase I) and a phenomenological study (phase II). The phase I was performed by a search on PubMed, Scopus, CINHAL and Web of Science, with the sub-aim to identify papers related to the lived experience of adolescents with CHD and their parents. The findings of the phase I represents the preliminary theoretical framework. The phase II (phenomenological study) will be conducted to validate the preliminary theoretical framework (phase I findings), customizing the same phase I findings to shape the semi-structured interviews for patients and parents, and using a purposive sampling.

Results: Seven papers were included (phase I), coming from a selection and assessment of 405 potentially relevant studies. These papers were analyzed, discussed and a qualitative meta-synthesis was performed. The meta-synthesis findings were 4 main domains, 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'. Those domains represents the preliminary theoretical framework to test with phase II (not yet implemented).

Conclusions: Our strategy to develop a CHD-specific scale for adolescents patients with CHD and their parents should help the delivery of a tailored care, where the needs assessment is helped by the use of a disease-specific tool.