

## MPN-3

### **CHD Parents Need Questionnaire (CHD-PNQ): development and validation of a protocol study amongst Italian population**

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#### Introduction.

Parents of Congenital Heart Diseases (CHD) patients play a pivotal role beneath the whole life of their children, both in their cure and growth process. In fact, the CHD parents are extensively involved in care activities, such as accompanying their child to visits, always staying with them for the entire time and administering their medications every day. Moreover, they help as integral members of their child's healthcare team and they give their children support for developing independence and promote their responsibility. Thus, being a parent with those responsibilities is very difficult due to stress, important dilemmas and contradictions. The assessment of those needs could be strategic to establish any shortage in this field. Currently, to the best of our knowledge, there is a lack of information in the literature about experiences and dilemmas of CHD parents, and knowing the needs of CHD parents is important to address a tailored and efficient health-care delivery for the whole family. Therefore, the purpose of this study is to develop and validate a tool (CHD-PNQ), evaluating CHD Parent's Needs, amongst Italian population.

#### Methods.

Three phases methodological study. Phase 1 concerns the drawing up of CHD-PNQ's items, based on literature review. Phase 2 tested content and face validity, aimed to investigate the clearness and the pertinence of the items, when translated in Italian. Content validity was assessed computing content validity ratio (CVR) and index (I-CVIs; S-CVI) from expert panelists' response. Face validity was assessed by the narrative analysis on the answers of three open-ended questions to the expert panelists. Phase 3 involved the data collection from a cross-section of CHD Italian Parents to assess the psychometric proprieties, stability and internal consistency of the CHD-PNQ

#### Results

This trial has approval from the San Raffaele Hospital (Milan, Italy) Ethics Committee (approval number: 136/INT/2017), and it will begin on January 2018, at IRCCS Policlinic San Donato.

#### Conclusion

The presented protocol study could allow the CHD Parents Need Questionnaire to be developed and validated. Moreover, the evaluation of CHD parents' needs could fill the gap in this area and providing an efficient health-care delivery for the whole family.