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

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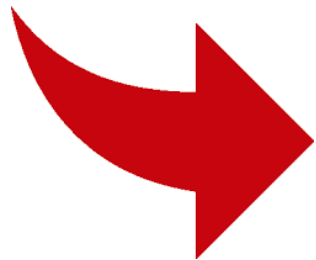


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Congenital Heart Disease:

To due the advances in diagnosis, medical technology, surgical interventions and treatments:

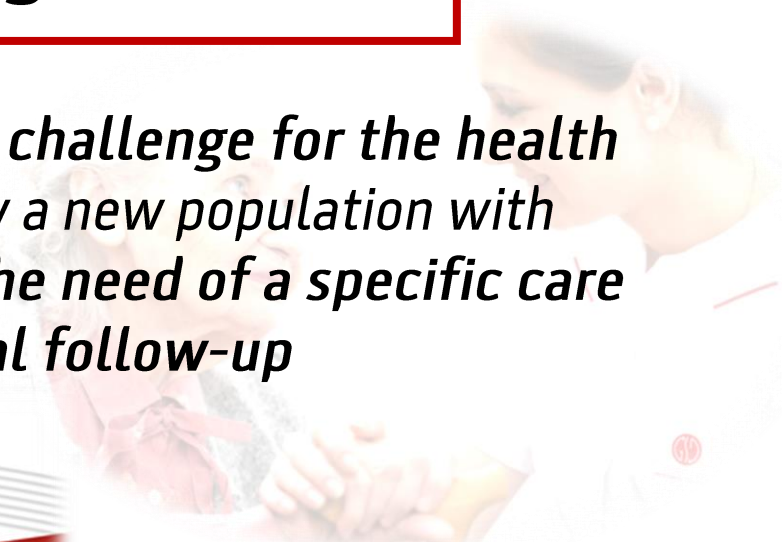
- **1.3 million children live with a CHD worldwide**
- **90% of them can survive into adulthood**
- **2800/million adults are currently living with CHD**



These patients represents a new challenge for the health care systems: they are relatively a new population with specific peculiarities, such as the need of a specific care planning and a life-time clinical follow-up



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The transition from childhood to adulthood is a crucial and complex process for every young person, and it is particularly important for CHD adolescents



CHD adolescents:

- must face the consequences of their disease and the need to be adherent with their follow-up indications
- could be exposed to many psychological issues related to their development of self-identity, self-esteem and self-image
- have to learn about their disease, overcome frustration and anxiety and develop self-care strategies for coexisting with CHD



the recent clinical management has focused to develop the transition care models that aim to provide self-management and to satisfy the medical, psychosocial, educational, and employment needs of CHD adolescents

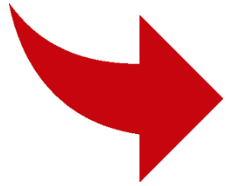


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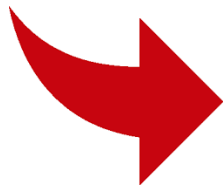




In this process, parents play a key role, being a landmark for CHD adolescents.



The CHD adolescents' 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



They help as integral members of their child's health care team and they give their children support for developing independence and promote their responsibility



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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.



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.



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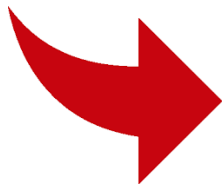
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Methods

The theoretical framework will be defined by a **two-phase methodological study**



The phase I was performed by a review of the literature, 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, that will tested with phase II with a phenomenological study



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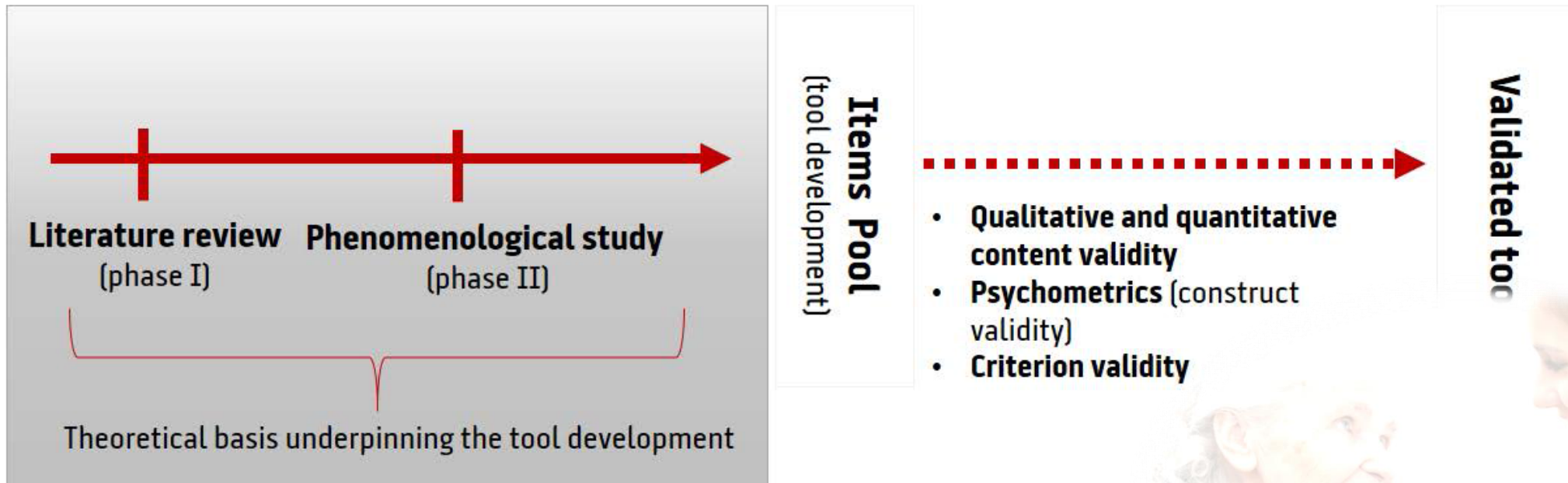




Methods



FIGURE 1. Development of a tool to assess CHD adolescents' and their parents' needs





Phase 1

The review literature through a literature search in the last 20 years, in accordance with the PRISMA guidelines and PICO's method. Databases searched included PubMed, Scopus, CINHAI and Web of Science and keywords used are "Congenital heart disease", "Parents", "Adolescents" and "life experience". Only the qualitative papers were included.



Phase 2

The phase II consists of a phenomenological study will be conducted to validate the preliminary theoretical framework described in the findings of phase I. By the findings of the phase I, the arguments of the semi-structured interviews for patients and parents will be shaped, using a purposive sampling

The findings of the phase I represents the preliminary theoretical framework.





Results



Phase 1

- *The search yielded 405 potentially relevant studies for screening, 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**

Phase 2

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.



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Thanks for the attention



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