

## Towards the Standardization of Transition Care Models for Adolescents with Congenital Heart Disease (CHD): A Perspective

Serena Francesca Flocco<sup>1</sup>, Rosario Caruso<sup>2\*</sup>, Federica Dellafiore<sup>2</sup>, Adelaide Orlando<sup>3</sup>, Arianna Magon<sup>2</sup>, Alessandro Giamberti<sup>1</sup> and Massimo Chessa<sup>1</sup>

<sup>1</sup>Pediatric and Adult Congenital Heart Disease Center, IRCCS Policlinico San Donato University Hospital, San Donato Milanese (MI), Italy

<sup>2</sup>Health Professions Research and Development Unit, IRCCS Policlinico San Donato University Hospital, San Donato Milanese (MI), Italy

<sup>3</sup>Italian GUCH Association, San Donato Milanese (MI), Italy

\*Corresponding author: Rosario Caruso, MSc, PhD, Head of Health Professions Research and Development Unit, IRCCS Policlinico San Donato, Via Agadir, 20-24, 20097 San Donato Milanese (Mi), Italy, Tel: +39 0252774940; Fax: +39 0252774969; E-mail: [rosario.caruso@grupposandonato.it](mailto:rosario.caruso@grupposandonato.it)

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### Abstract

This perspective paper is aimed to describe an Italian experience related to the empirical implementation of Congenital Heart Disease (CHD) transition care models, highlighting the most significant author's perspectives. The CHD transition care models implementation strategy adopted at Policlinico San Donato (Italy) is closely linked to the clinical practice and to the research activity at national and international level. This strategy could be an efficient start-up to boost the understanding of the adolescent patients' needs, also giving more evidence to the effectiveness of the transition care models.

**Keywords:** Adolescents; Congenital heart disease; Perspective; Transition care models; Transition care clinics

### Introduction

Congenital heart disease (CHD) is defined as 'a gross structural abnormality of the heart or intrathoracic great vessels that is actually or potentially of functional significance' and it is the most common congenital anomaly with a worldwide prevalence of 9 per 1,000 live births [1]. Considering the improving of the diagnosis, the surgical and the overall medical approaches, the literature shows that up to 90% of CHD surgically treated infants survive with the possibility to grow until the adulthood [2,3]. For this reason, the grown-up congenital heart disease (GUCH) patients (i.e. patients aged  $\geq 18$  years) are increasing worldwide [4], being a relatively new population with important peculiarities, such as the need of a specific care planning and a life-time clinical follow-up [5].

The majority of research focuses on the CHD childhood clinical management [6] or on the CHD adulthood challenges (i.e. GUCH challenges) [7]. The literature has paid attention to explore the peculiarities of the transition period from childhood to adulthood in patients with CHD, barely in the last few years [8,9]. Some recent studies present different transition care models, including generic and disease-based models [10,12], but there is a shortage of literature aimed to present implementation experiences and perspectives related to those models.

### Background

The transition care models have to orient and encourage a sound health-behavior [10-13], considering how these patients could be exposed to many psychological issues related to their development of self-identity, self-esteem and self-image. The main psychological issues among adolescents with CHD are given by: (a) modification of their body image (e.g. scars); [14] (b) social functioning (e.g. family or peers

relationships) [15]; (c) increased risk of anxiety, diminished self-esteem and depression, often associated with their personal problems internalizing [15,16]; and (d) problems concerning smoking, alcohol or illicit drugs consumption, and sexual behaviors [17,18]. Some authors show how smoking and alcohol or illicit drugs consumption among adolescents with CHD are comparable with consumption among adolescents without CHD [17].

The behavior of adolescents with CHD is more likely influenced by their peer relationships rather than their clinical condition. Indeed, the adolescents with CHD seem to pay less attention than their peer to some health-promoting behaviors, such as physical exercise or dental hygiene [17,19]. Moreover, the relationships between parents and adolescents with CHD seem to have some peculiarities, which are recently highlighted in the findings of a literature meta-synthesis of qualitative studies where some contradictions emerged, such as the parents' hyper-responsibility and overprotection versus the adolescents' independence desire [20].

The American Academy of Pediatrics defines the main goal of the transition process as to optimize lifelong function through high-quality and uninterrupted services [21]. According to that important milestone, the recent literature presents some transition care models, which can be generic [11,22] or CHD specific [5,8-10,12]. The CHD specific models consider: (a) timing of transition (i.e. the process starting individualization, according to each patient's medical and developmental conditions); (b) assessing the disease pattern, where both the un-operated CHD patients (i.e. unrecognized or undiagnosed during childhood) and the CHD patients undergo corrective or palliative surgery during childhood should be assessed; and (c) care planning, involving local hospitals closely linked to the specialist centers with a transition clinic [23].

In recent years, the literature shows an increasing number of papers aimed to propose CHD transition care models [5,7-10,12,23,24]. However, there is little empirical data showing the effectiveness of

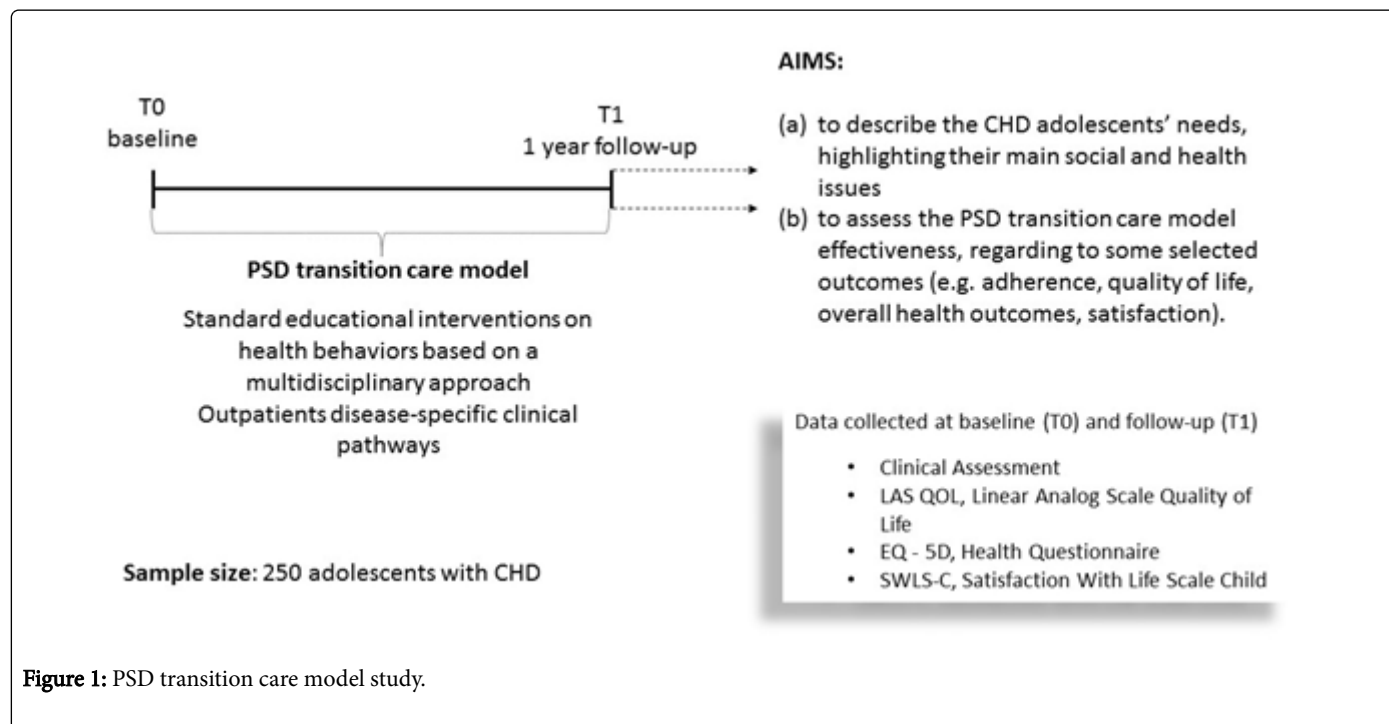
these models. Indeed, to the best of our knowledge, there are no papers aimed to share their perspective and experience on the implementation of these models. Therefore, the aim of this work is to describe the experience of Policlinico San Donato (PSD) clinicians regarding to the empirical implementation of CHD adolescents' transition care model, highlighting the most significant author's perspectives. PSD is an Italian teaching hospital and a specialist center for CHD patients.

### The CHD transition care model implementation at PSD: experience and perspective

There is lively debate regarding the organization of the distribution of healthcare centers involved in CHD care [25], especially regarding which organizational characteristics and competencies are needed to be a CHD specialist center, because the whole care process for these patients is very challenging [26]. Approximately 500 patients with CHD are surgically treated every year in PSD; 368 of them are under 18 years old and 41 patients are 11–18 years old (i.e. adolescent patients). In the last 10 years of care activities, beyond the traditional attention that PSD clinicians have paid to CHD paediatric patients [27] or GUCH [28,29], they are also paying more attention towards the adolescents, since they cannot be considered neither 'big kids' nor 'adults' [4].

PSD clinicians' attention to adolescents with CHD is the interim result of a paradigm shift, which is still driving their overall implementation of the CHD transition care model. This approach is in accordance to the CHD disease-specific theoretical descriptions available in the literature [5,8–10,12,19,24]. Moreover, the patients' needs represent the PSD care delivery core of the CHD transition care model, while the multidisciplinary and the multi-professional approaches represent the paradigm of care.

The project implementation officially began with Ethical Committee approval (36/INT/2015) of a research project in April 2015. The problem underpinning the whole research project, and thus the overall implementation of the CHD transition care model at PSD, is given by the significant gap in knowledge regarding the worldwide lack of data showing the effectiveness of these models and their impact on patient health outcomes (e.g. follow-up adherence; medical outcomes; psychosocial outcomes; nursing outcomes). For this reason, PSD clinicians have chosen to closely link the transition care model implementation to a research project aimed to: (a) describe the adolescents needs with CHD, highlighting their main social and health issues; and (b) to assess the model effectiveness regarding some selected outcomes (e.g. adherence, quality of life, overall health outcomes, satisfaction) (Figure 1).



**Figure 1:** PSD transition care model study.

Besides the production of new knowledge, this implementation strategy (i.e. the close link between clinical practice and research) could lead to some cultural benefits because the research protocol concerns all healthcare professionals involved in the care of adolescents with CHD, facilitating the cultural shift needed to implement a transition model. The authors may also speculate that this research project will also drive the development of patients' paths, based on the mapping of the main patients' health issues related to their clinical condition and their CHD. These paths are clinical (e.g. outpatient disease-specific clinical pathways) and educational (e.g. clinical bundles), and they are also aimed to standardize the practice. The

standardization of these paths could also help the clinicians to deliver tailored care, since the standardization allows the dedication of more staff members and organizational resources to help identify the patient's peculiarities, beyond some critical common issues related to their clinical condition. More specifically, the standardization of these paths concerns: (a) the patients' categorization; (b) the healthcare professionals' competence in mapping and improving [30,31]; (c) the patients' self-management improving; and (d) the development of a functional clinical data collection system [32].

## Conclusion

The understanding of patients' needs is crucial to face the diversity and complexity of adolescents with CHD. It will guide the whole care delivery, being the common mould for all the professionals involved within the care process. Further empirical investigation is necessary to fully understand these needs and give an evidence-based basis to the models. For this reason, the authors believe that the CHD transition model implementation strategy presented in this paper, where the clinical practice is closely linked to the research activity, could be an efficient start-up to boost the understanding of the adolescent patients' needs, also giving more evidence to the transition models.

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