Background

Congenital heart diseases (CHD) are one of the most prevalent and serious birth defects, representing a major global health problem. With a prevalence of 9.1 for 1000 live births [1], the CHD are the leading causes of birth defects–associated morbidity, mortality, and medical expenditures [2]. Currently, 1.3 million children live with a CHD worldwide [3] and approximately 90% of them can survive into adulthood [4], due to the advances in diagnosis, medical technology, surgical interventions and treatments. It is estimated that about 2800/ million adults are currently living with CHD [5], which need a lifelong follow-up [6].

The transition from childhood to adulthood is a complex process for every young person, being particularly important for CHD adolescents. In fact, the adolescence is a crucial phase for the formation of the personality [7], during which the CHD adolescents have to face with the consequences of their disease and the need to be adherent with their follow-up indications [10]. Moreover, during the transition into adulthood, CHD adolescents could be exposed to many psychological issues related to their development of self-identity, self-esteem and self-image [8] and they should learn about their disease, overcoming frustration and anxiety and developing self-care strategies [9]. For this reason, the recent clinical research focused to explore the peculiarity of the transition period...
from childhood to adulthood in patients with CHD, in order to
develop the purposeful transition care models, which are
aimed to provide self-management and to satisfy the medical,
psychosocial, educational, and employment needs of CHD
adolescents [1,8].

In this process, parents play a key role, being a landmark for
CHD adolescents [10]. In fact, 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 [11].
Moreover, they could be considered to be an integral part of
team members for their children [11], supporting them to
develop their independence and to promote their responsibility
[12].

Currently, there is a lack of information about the
experiences and dilemmas of parents during the CHD transition
process from childhood to adulthood. Recent findings seem to
highlight that it is not easy to be a CHD adolescents’ parents,
because they experience anxiety, stress, and depression [13],
often feeling uncertain about their roles during transition
[14]. However, knowing the experiences of CHD adolescents’
parents is important to address tailored and efficient health-
care delivery for the whole family. Therefore, the aim of this
study is to synthesize qualitative papers of life experience of
CHD adolescents’ parents.

Materials and Methods

Review method

A literature review with meta-synthesis was undertaken to
address the following research questions:

♦ What are the experiences of CHD adolescents’ parents?

♦ Which factors influence the life of CHD adolescents’
parents?

Meta-synthesis is a relatively new technique for examining
different qualitative research [15]. The literature shows different
approaches and techniques types to conduct a meta-synthesis
[16]. Noblit and Hare’s [17], meta-ethnographic approach
was used to guide this meta-synthesis, subsequently adapted
for health services research by Britten et al. [18]. This meta-
synthesis method includes 7 phases (Table 1), that overlapping
as the synthesis proceeds: phase 1 – getting started; phase 2 –
deciding what is relevant to the initial interest; phase 3 – reading
studies; phase 4 – determining how the studies are related; phase
5 – translating the studies into each other; phase 6 – synthesizing
translations; phase 7 – expressing the synthesis [17].

Search strategy

In accordance with phase 2 [17], a systematic search
was performed in electronic databases including MEDLINE,
PsycINFO, CINAHL, and Google Scholar, in December 2015.
Before the begin of the systematic search process, a pilot test
was carried out in electronic databases to exclude that a meta-
synthesis on CHD adolescents parents was already performed
and to identify the key words. The relevant key terms used to
shape the queries were as follows: ‘Congenital Heart Disease’,
‘Transition’ ‘adolescents’, ‘parents’, ‘Life experience’. Indeed,
the search comprised four separate search queries based on
thesaurus terms, free-text terms and broad terms relevant
to topics searches: (1) population-related terms (Parents,
Parenting, Caregivers, Family); (2) transition phase-related
terms (Adolescents, Youth, Transition phase, Transition); (3)
ilness – relation terms (Congenital Heart Disease, Congenital
Heart Defects); (4) outcomes-related terms (Life Experiences;
Perception; Life Change Events; Quality of life, Health related
quality of life, Experience, Life). Afterwards, the search terms
were combined using the Boolean terms ‘OR’ and ‘AND’ and
further combined using free text search. The time limit was
set to 1995–2015, because the advanced cardiac surgery was
developed and the CHD adolescents there was not before to 20
years ago. Other search limits were the English language and
the full text availability.

Inclusion and exclusion criteria

The review included primary qualitative studies about the
experiences of CHD adolescents’ parents. The studies identified
by queries was selected considering the following inclusion
criteria: (a) qualitative studies, (b) published between January
2005 and December 2015, (c) written in English, (d) available
full text, (e) focus on parents of CHD adolescents, and (f)
explore their life experiences. Studies with other outcomes,
with theoretical or quantitative design, in languages other than
English were excluded.

Search process and quality appraisal

The search process was conducted by two authors (DF and
DR) independently. The authors have discussed frequently
to reach agreement on the search process and appraisal. The
procedure to select the articles during search is summarized
in the flow diagram, according to the PRISMA flow-chart
(PREFERRED REPORTING ITEMS FOR SYSTEMATIC REVIEWS AND META-
ANALYSES) [19], as shown in Table 2. The depth literature search,
performed using the key terms, led to identify 386 articles
(identification phase). In the screening phase, 246 articles
were excluded using the inclusion criteria, such as time limit,

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synthesis. Arch Nurs Pract Care 3(1): 031-037. DOI: http://dx.doi.org/10.17352/anpc.000022
Table 2: Article search flowchart.

mother says “What worries me most is smoking, because I think is the only thing I can change” [25].

**Theme 2: parents’ hyper-responsibility and overprotection versus adolescents’ independence desire**

This theme described the contrast between the parent’s inclination in taking charge of adolescent’s responsibilities and their wish of getting their own children more independent. Parents expressed ambivalence about whether it was appropriate to encourage their child to prepare for the working world. Jane’s mother said: “I’d like to see her graduate from eighth grade and high school. I really would like to see her have the skills she needs to pursue what she would like to do in life... I guess the health I can’t really worry about, because! Can’t do anything about it...” [25]. The transition phase included the transfer of responsibility from pediatric care to the adult one, and represented the period in which parents start to give more autonomy in decision making to the young adult. Some families consider this situation as a difficult and intense period, and they would like that their child will never grow up; but, at the same time, they realize how this transfer is considered as a fundamental step, in which they need to release responsibility and independence to their children [26,27].

Parents’ natural desire is to act as a parent: they feel the need to be involved in the care of the adolescents and feel entitled to responsibility for their adolescents’ health. They grieve the experiences that their sick children are missing because of their heart defects and mourn the tough school years that they must undergo. They also express concerns that the world would not treat the young adult fairly because of CHD [25]. Parents become aware that their children were no longer entitled to responsibility for their adolescents’ health. They need to be involved in the care of the adolescents and feel its urgent responsibility.

**Theme 3: desire to give support, but not to be supported**

This third theme described the parents’ need to help their child with CHD and the relationship of the family with the care
Parents would like to be considered as a normal family: despite copious clinical visits, surgeries, or unexpected health deterioration of health, some parents attempt to adapt themselves to the new life, “normalizing” as much as possible, as suggested by health care providers [26]. Others parents, instead, tend to make a comparison between their own children and healthy peers, because schools and society are the first to define the adolescents affected by CHD as “sick” and then different [24, 25]. John’s mother was frustrated by the discrimination her son encountered from a teacher: “We always said we never restricted John, we always felt that if he got tired, he would just stop doing it. And so I told the PE teacher... and of course that didn’t fit into their way of thinking... And instead of doing PE, he was benched every time. Benching there was punishment... And I went to the teacher and I said, ‘Don’t you have anything else for him to do? Could he be your assistant? Or help with the balls?’ And she said, ‘No, no, because that would give him a favorable position. That wouldn’t be fair towards the other kids.’ So, we got out of that school.” [25].

Parents suffer thinking about the experiences their children are losing [28]: they perceive that CHD adolescents feel alienated and treated differently by teachers and coaches [29] and feel that the illness has affected all family life, even in the smallest aspects. In the articles by Gantt (2002) a mother states: “We used to go camping before he was born. We never went again. Not as a family. Not like we did with the other two kids.” [26]. Parents also ask themselves how to inform family and friends about their children’s disease; others use instead the disclosure of the disease to vent themselves and to be considered, after all, normal [25]. Most parents testified in qualitative articles of trying to live life as it is, encouraging adolescents to love and appreciate it, despite the physical and social limitations imposed by congenital heart disease: “He’s just a normal child. So, we always try to be normal with him; (or) you have to let yourself forget about the heart problem in order to go on through life; (and) Live normally. Let your family continue on as normal as possible, because the rest of the world is not going to give one hoot that this kid’s got this defect, so don’t let him use it as an excuse. Think positive, hold the vision of good results.” [25].

Discussion

These six articles, analyzed by meta-synthesis approach, provide valuable information on the factors influencing the life of CHD adolescents’ parents. These information could be used to better address a tailored and efficient health-care delivery for the whole family. Currently, literature has paid little attention to this topic, in fact the scientific researches are mainly focused on quality of life of CHD patients, while the experiences of CHD adolescents’ parents are less studied. Moreover, the literature about CHD adolescents’ parent’s life experiences appears fragmented. Regarding this theme, the research strategy described in this paper, has identified only six articles that explored this topic in the last 20 years. According to Noblit and Hare’s meta-ethnographic approach [17], the synthesis of the included six qualitative papers seems to bring out a persistent experience of contradictions lived by parents during the transition phase of the adolescents affected by CHD.

Four themes emerged by the results of the six qualitative papers to synthesize the life experience of CHD adolescents' parents: “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”. The issue of contradictions is the main feature characterizing all the peculiarities of CHD adolescents’ parents. Following the reading of the included papers, different divergent views emerged by the perspectives and experiences described in the original qualitative articles: (a) the parents wish to have a normal life, similar to life of healthy sons, but they must face every day the limitations imposed by illness on quality of life of the young and on family context; (b) they would like to support the sons but they demand to be supported by care providers; (c) they give a hyper-responsibility and overprotection to teenager but, in opposite, the adolescents would want their independence; (d) finally, they are uncertain and frightened about the future of their sons, but they can implemented the positive coping strategies to normalize the life of them and their CHD sons, as more possible.

These issues suggest that some difficult and significant dilemmas are present in the life of adolescent with CHD parents, especially during the transition phase from childhood to adulthood. Furthermore, parents highlight their need to be supported by care providers to best face the transition phase of their CHD sons. Nurses play a crucial role in this process, because their care delivery should be addressed to both adolescent patients and their parents. Moreover, nursing care could provide continued contacts between physician, patients and their families during all their lives.

According to the recent guidelines ACC/AHA for the management of patients with CHD [30], the process of transitioning should prepare young patients for successful transfer to an adult healthcare provider at a later time, and it should begin since the age of 12 [31]. Furthermore, the transition care models have to orient and to encourage a sound health-behavior, considering how those patients could be exposed to many psychological issues related to their development of self-identity, self-esteem and self-image [8].

Moreover, heavy medical expenses [32] and frequent hospitalizations [33], bring CHD adolescent patients and their family members to other types of complications, from the burden of the disease on the whole family [34], to issues related to the unknown future, treatment program or prognosis. For these reasons, the understanding of CHD parents’ needs is crucial to face the diversity and complexity of adolescents with CHD, guiding the whole care delivery.

As many studies have already shown, parents of children with CHD showed lower well-being compared to parents of healthy children [35]. These findings are amplified when children with CHD will grow up. For all these reason, the literature shows that the parental role during the transition phase is extremely difficult, being the parents a landmark for their children. They live feelings of helplessness, they are unable to relate and understand the needs of their sons, and consequently parents of CHD adolescents have a decreased well-being compared to parents of healthy adolescents.

Limitations

This meta-synthesis was developed based on data collected within original studies on the experiences of CHD adolescents’ parents. Therefore, this study’s quality is largely a product of the quality of data collected in the original studies chosen for meta-synthesis. A strength of the current study was that the two authors conducted their reviews independently and are compared for confirming data. While the integration of different individual’s perspectives and experiences has not altered the focus of this study, it produced a more complete picture of the study phenomenon. On the contrary, the inclusion of only six qualitative papers is the main limitation of this meta-synthesis, which is not intended to be comprehensive or cumulative. Nevertheless, the literature has paid little attention to date regarding this issue, also in light of the relatively new interest in this field. In other words, this meta-synthesis represent a first attempt to incentive research endeavors to study the issue around the life of adolescents with CHD and their parents.

Conclusion

This meta-synthesis help to highlight the peculiarities of adolescents with CHD, their parents and should be useful even for health providers. In fact, the role of parents is crucial in the transition to adulthood of their children with CHD, especially to personalize their clinical pathway. For this reason, the understanding of the CHD adolescent’s parents life experience is fundamental to provide nursing care focused on unanswered or hidden needs. As described in this meta-synthesis, the continuous experience of contradictions lived by CHD parents during this transition phase should be the beginning to shape personalized support programs. Moreover, those contradictions represent a real theoretical framework that have to be deeply investigated with empirical researches.

In other words, the results of this meta-synthesis could help to frame the peculiarities of adolescents with CHD and parents, addressing future empirical studies and even the necessity to develop specific tools to measure each identified peculiarity.

References
