


# BMJ Open Exploring the lived experiences of pregnancy and early motherhood in Italian women with congenital heart disease: an interpretative phenomenological analysis

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## ABSTRACT

**Objective** This study explored the lived experiences of women with congenital heart disease (CHD) during pregnancy and early motherhood.

**Design** Qualitative study using semistructured interviews. Data were analysed according to interpretative phenomenological analysis.

**Setting** San Donato Milanese, Italy.

**Participants** 12 adult women during pregnancy or early motherhood.

**Results** Three main themes emerged from the analysis that were labelled as follows: ‘Being a woman with CHD’; ‘Being a mother with CHD’; and ‘Don’t be alone’. Mothers described both positive and negative feelings about their pregnancies and transitions from childless women to mothers with CHD. They needed supportive care to improve the management of their health during pregnancy and early motherhood.

**Conclusion** This study explored the lived experiences of women with CHD during pregnancy and early motherhood. The emerged themes represent an initial framework for implementing theory-grounded educational and supportive strategies that improve self-care, engagement and quality of life for women with CHD. Furthermore, the study’s results provide guidance for operationalising the described experiences into items and domains for future cross-national surveys.

## INTRODUCTION

Congenital heart disease (CHD) is defined as a structural abnormality of the heart and the great vessels, showing a birth prevalence of 8 cases per 1000 live births (prevalence ranges from 3% to 10‰).<sup>1</sup> CHD represents 0.8%–1.2% of all congenital birth defects.<sup>2</sup> There is consensus among clinicians in classifying the structural abnormality of the heart and great vessels using a three-level classification—that is, simple, moderate and complex CHD.<sup>3</sup> In Italy, some regional registries have indicated that the birth prevalence of CHD ranges from 3.5% to 11‰ of live births.<sup>2 4–6</sup> Given the lack

## Strengths and limitations of this study

- The adopted interpretative phenomenological analysis allows the researchers to obtain rich and complex data that provide new insights into understanding the experiences of women with congenital heart disease during pregnancy and early motherhood.
- This study investigates a scenario that is currently unexplored.
- The qualitative approach does not allow generalisation.
- This study uses an exploratory approach, which requires further investigation with larger sample and multiple methodologies.

of epidemiological and longitudinal data in Italy on patients of all ages with CHD, data from the Italian regional registries are pivotal for highlighting the characteristics and epidemiology of CHD in the country. Accordingly, as per regional registries, adults with CHD who present functional limitation during physical activities (New York Heart Association class 2 or higher) compose roughly 35% of the population with the disease, while in 15% of cases, a history of recurrent arrhythmias is described in anamnesis, and patients were treated using oral anticoagulants 12% of cases.<sup>6</sup>

Overall, more than 85% of children with CHD live to adulthood due to the advancements in medical and surgical treatments.<sup>7</sup> Accordingly, literature has emphasised the need for children with CHD to have a smooth and evidence-based transition from childhood to adulthood in order to optimise their quality of life as adults, as well as to prevent health-related risks associated with individual lifestyles.<sup>8–10</sup> Recently, it was reported that the lifestyles of Italian adults



with CHD are comparable to the lifestyles of the general population, including in relation to the prevalence of unhealthy behaviours, such as smoking or recreational drug consumptions.<sup>10</sup> The similarities of the unhealthy lifestyles between adults with CHD and the general population are also relevant to the challenges faced by women with CHD during pregnancy and after childbirth.<sup>11</sup>

Overall, the number of women with CHD who are becoming pregnant is increasing worldwide.<sup>11</sup> In this population, pregnancy is typically contraindicated, and consistent contraception use is widely recommended by clinicians<sup>12</sup>: in fact, the haemodynamic changes associated with pregnancy could negatively affect women with CHD as well as their offspring,<sup>13</sup> even in cases of women with simple and moderate CHD who could exhibit sufficient cardiac reserve to successfully tolerate the physiological changes related to pregnancy.<sup>14,15</sup> Overall, the risk of complications is broadly associated with the complexity of CHD and diverse risk factors, such as lifestyles.<sup>13</sup>

Furthermore, pregnant women with CHD often experience feelings of fear for themselves and for their future offspring.<sup>16</sup> For these patients, the multidisciplinary case management of pregnancy and early motherhood is crucial for the achievement of better health outcomes and the guarantee of their safety.<sup>13,17</sup> A sound case management approach requires a clear understanding of the patients' in-depth experiences during pregnancy and early motherhood.<sup>9,18</sup> While the experiences of pregnant women with non-congenital cardiac disease appears to be sufficiently described, the literature has historically paid very little attention to the study of the multiple physical and psychological challenges that are experienced by women with CHD in pregnancy and early motherhood.<sup>10</sup> For instance, Claessens *et al*<sup>19</sup> highlighted that women with CHD struggled with themselves and their environment to be accepted as normal by the family members and healthcare providers. Further, Ngu *et al*<sup>20</sup> described high levels of concerns among women with CHD about the health risks associated with their clinical status and that of their children.

Overall, the experienced feelings, beliefs and concerns of these patients could represent an initial framework for developing theory-grounded strategies that support pregnant women with CHD. The lack of research on the experiences of women with CHD during pregnancy and early motherhood also undermines the possibility of designing surveys to map the healthcare needs of these women. Therefore, this study is aimed at exploring the lived experiences of women with CHD during pregnancy and early motherhood.

## MATERIALS AND METHODS

### Design, study population and data collection

This study has a qualitative design, which is consistent with interpretative phenomenological analysis (IPA).<sup>21</sup> The study was performed and reported following the 'Standards for reporting qualitative research: A synthesis

of recommendations' (see online supplementary file 1).<sup>22</sup> A purposeful and consecutive sampling was used to increase the likelihood of including participants who were able to provide meaningful and experiences. The inclusion criteria were: (1) women with diagnoses of CHD according to the recognised clinical criteria,<sup>3</sup> (2) women who were pregnant or in the stage of early motherhood, (3) possession of competence necessary to give consent to participate in the study and (4) spoken fluency in Italian. Women under the age of 18 years with CHD were excluded, as well as patients with cognitive impairments.

Eligible participants were identified and enrolled by the healthcare providers of a hub centre for the treatment of CHD in Northern Italy. Accordingly, the healthcare providers contacted the eligible patients, explained to them the aim of the study and offered information based on their interest in being enrolled. New participants were enrolled for as long as was needed to obtain the information required for the analytical process.<sup>21</sup> According to the IPA methodology,<sup>21</sup> the overall required sample was small and homogenous.

In accordance with IPA methodology, data are obtained from a purposive, homogeneous sample and the most common data collection method is the in-depth semi-structured interview.<sup>23</sup> Semistructured interviews were thus performed for the data collection. This type of interview was chosen because it is particularly informative, allowing the researcher to create the outline for the topics covered. However, the interviewee's responses determine the way in which the interviews are directed.<sup>24</sup> This is the most commonly used type of interview in qualitative health research, and it has the objective of allowing new viewpoints and issues to emerge freely. Moreover, the semistructured interview guide provides a clear set of instructions for interviewers, and, at the same time, it can provide reliable and comparable qualitative data.

Interviews were conducted face to face by an author (TN) who received specific training in the performance of this technique. The interviewer did not know the identities of the study's participants, and the setting was the ambulatory of the involved facility. Each patient signed a written informed consent form in order to be included in the interview session. The interviews were performed between April and September 2018. Participants were interviewed alone, enabling them to speak freely without being influenced by other persons, such as parents or spouses.

The interviewer invited each participant to give an in-depth description of their feelings and experiences, starting with an open and general question, such as: 'Please, can you describe the experience of your pregnancy?' Then, the interviews took the form of a free conversation, using reflections and open-ended questions to facilitate the discussion. The interviewer investigated the participants' experiences regarding the impact of living with CHD and their experiences of pregnancy, trying to highlight their feelings, changes, challenges and expectations. According to the used methodology, there

### Box 1 Interviews' guide for mother with congenital heart disease (CHD)

1. Please, can you describe your experience with the birth of your child?
2. What does it mean for you to be a mother with CHD?
3. What are your main concerns about being a mother with CHD?
4. What are the main difficulties to being a parent with your CHD?
5. What are the main needs that you perceive and live to being a parent with CHD?
6. What are your thoughts and feelings about your future and your child's future?
7. What are the challenges you, with your CHD, will face in raising a child?
8. What are the factors related to your CHD that, in your opinion, will influence the growth and life of your child?

was no strict interview guide,<sup>21</sup> but prompts and questions were used to explore the participants' experiences, as well as the barriers and facilitators of living through their pregnancies and early motherhood. Some examples of questions asked in the interviews are shown in [box 1](#).

During each interview, the investigator adopted an empathetic attitude towards the participant. When interviewed women seemed to have nothing more to say, the interviewer asked if they would like to add anything further. As instructed by Corbin and Strauss,<sup>25</sup> we did not stop data collection until a participant had nothing to add or until the open-ended questions no longer gave rise to any new information (ie, data saturation). For this reason, data collection ceased at 12 participants. Interviews lasted between 45 and 90 min. No repeated interviews were conducted (ie, a cross-sectional approach in interviewing). Furthermore, the interviews were audio recorded and transcribed verbatim by the research team.

#### Data analysis and rigour

Data were analysed using IPA,<sup>21</sup> a methodological approach widely adopted by nursing researchers to uncover the lived experiences of the enrolled participants. IPA's aim is to deeply explore participants' attributions of meaning regarding their experiences on both personal and societal levels. The phenomenological aspect of IPA acknowledges that people can provide meaning to their experiences.<sup>21</sup> The purpose of this qualitative approach is not to test out a previously defined hypothesis or to achieve maximum variation, in order to produce a theory from the data. Instead, the overall aim in IPA is to translate the emerging master themes into an interesting and relevant narrative account of the phenomenon under investigation. It is important that the researchers' accounts have been derived from what has actually been said by the participants; thus, verbatim extracts from the participants' interviews are included in the manuscript to provide a means of validation.

The investigators involved in the data analysis bracketed their presuppositions before data collection. A critical reflection technique that is part of the IPA methodology

is 'bracketing', which requires each researcher to write down all of their preconceptions about the phenomenon under investigation. In the interpretative approach of phenomenological research, the researchers' points of view can affect data analysis, but bracketing strengthens the rigour of such findings and reduces the chance that the researchers' thoughts and points of view will influence their understanding of the participants' perspectives.

In accordance with Smith *et al*,<sup>21</sup> the interview transcripts were subjected to a detailed, case-by-case systematic qualitative analysis, performed independently by two authors (SB and TN) to obtain full immersion in the data as well as to create familiarity with both the breadth and depth of the content. The first transcript has been read and examined a number of times and, with each reading, the researcher marked the transcript with initial descriptive, linguistic and conceptual comments. The next stage of analysis involved transforming these comments into overarching themes that captured the essential features and relevant meanings in relation to the research question from the initial readings. Subsequently, connections were developed between themes until a coherent and organised thematic account of the case was established. Connections across cases were made until a set of superordinate themes for the entire data corpus emerged. Each superordinate theme was connected to the underlying themes, which, in turn, were connected to the original annotations and extracts from the participants. An independent researcher (FD) carried out validity checks of the analyses and interpretations. Following these checks, non-significant and/or overlapping themes were discarded or subsumed to create a master list of superordinate and subordinate themes. Finally, the table of superordinate themes was translated into a narrative account where the themes have been outlined, exemplified and illustrated with quotations from the participants' interviews.

Furthermore, in accordance with the IPA guidelines, the authors have applied the processes of credibility, transferability and dependability to ensure rigour.<sup>26</sup> 'Transparency and coherence' were established through the provision of clear individual summaries about each interview. These were shared with four participating mothers, who were asked to read the summary and share any additional information. This process of 'member checking'—along with field notes, transcription directly after each interview and a comprehensive audit trail—helped to further ensure methodological credibility.<sup>27</sup> The results, including quotations, were translated from Italian to the target language, English, while following the recommendations to achieve optimal representation of the participants' experiences.<sup>28</sup> To ensure reliable translations, we asked an English expert to revise the contents as needed.

#### Ethical considerations

The institutional review board of Ospedale San Raffaele (protocol number 136/INT/2017) approved the research protocol. The work has been carried out in accordance



with the code of ethics of the World Medical Association (Declaration of Helsinki). Participants were assured that confidentiality would be maintained at all times. The interviews were conducted in a private, quiet space in the hospital, and participants were free to leave the study at any time. All participants were informed through a detailed sheet of paper outlining the aims of the study; the researchers read the material carefully and explained the process prior to each interview. After participants provided written consent, the investigators assigned a number to each patient, hiding their identities.

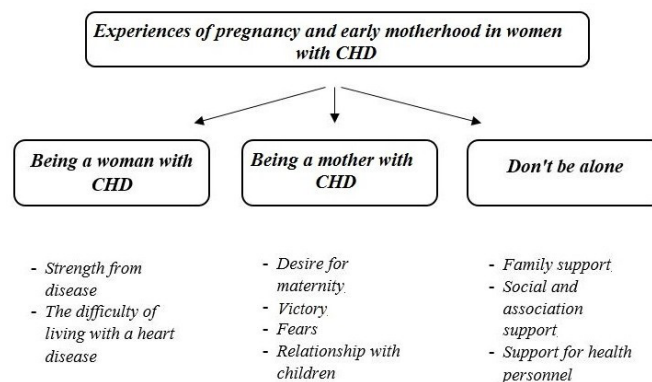
### Patient and public involvement

Neither patients nor the public were involved in the designing of this research, although both will be informed of the study's results via the network of the Italian Association of patients with CHD (Associazione Italiana Cardiopatici Congeniti Adulti (AICCA)). Accordingly, the authors will employ the AICCA's support to disseminate the study's results.

### RESULTS

The 12 participants were all white Italian women between the ages of 32 and 54 years. At the time of the study, only one woman was 9 months' pregnant, while the other 11 participants were mothers of sons or daughters. All but one lived with a spouse, and the average age of the mothers was 40. According to the classification defined by Warnes *et al.*,<sup>3</sup> most women had CHD with moderate severity (n=6), while four of them had simple CHD. Two mothers were affected by CHD with a complex severity, such as pulmonary stenosis (table 1). Further demographic information has been concealed to protect confidentiality.

Three main themes emerged from the analysis of the interviews. Quotations from the interviews with participants have been translated by the authors into English



**Figure 1** Summary of themes and subthemes. CHD, congenital heart disease.

purely for publication purposes. To guarantee a faithful and reliable translation, we asked a bilingual expert to revise the content.

A detailed description of these themes follows.

1. Being a woman with CHD: this theme involves the positive and negative feelings participants experienced before pregnancy as well as how difficult it was to live with their state of health and how strong their condition had made them emotionally.
2. Being a mother with CHD: it is a matter of living with one's own disease, and facing a pregnancy knowing that there can be risks and/or complications and uncertainly regarding being able to raise a child.
3. Don't be alone: from all the interviews, we extrapolated the importance of familial, societal and health practitioners' support in terms of participants being able to make the best of their condition as women and mothers with CHD.

Each theme included different subthemes, which are summarised in figure 1.

**Table 1** Participant characteristics

ID mother	Age	Diagnosis of CHD	CHD classification
1	34	Pulmonary stenosis	Complex severity
2	54	Tetralogy of Fallott	Moderate severity
3	50	Tetralogy of Fallott	Moderate severity
4	48	Atrial septal defect	Simple severity
5	50	Tricuspid atresia	Moderate severity
6	33	Atrial septal defect	Simple severity
7	34	Tricuspid atresia	Moderate severity
8	47	Tetralogy of Fallott	Moderate severity
9	35	Patent oval foramen	Simple severity
10	32	Pulmonary stenosis and atrial septal defect	Simple severity
11	32	Bicuspid aortic valve and coarctation	Moderate severity
12	39	Pulmonary atresia with ventricular septal defect	Complex severity

CHD, congenital heart disease.

### Theme one: Being a woman with CHD

Each patient interviewed expressed that ‘before being a mother, I am a woman with congenital heart disease’. Additionally, ‘being a woman with a CHD’ has influenced and conditioned, both positively and negatively, every aspect of the participants’ lives; as a result, it has also influenced the desire for and experience of pregnancy and motherhood. Specifically, the interviews revealed positive and negative feelings that patients had experienced before becoming mothers, focusing the story on their past and life experiences with CHD. Often, being forced to live with CHD had allowed patients, through daily trials and labours, to grow and recognise how strong temperamentally they are. This theme emerged from two specific subthemes, ‘Strength from disease’ and ‘The difficulty of living with a heart disease’. From the interviews emerge the mechanisms that underlie the possible reactions that a person may have to a traumatic event: the coping strategies activated—that is, the ways in which they adapt to stressful situations—can have a positive or negative outcome. Therefore, this adaptation process is either a functional/adaptive or dysfunctional type, the latter of which leads to an increase in stress.

With regard to the first subtheme ‘Strength from disease’, often, the mothers interviewed expressed that they had framed their heart disease as a challenge won. Despite the numerous moments of difficulty and fatigue they perceived, they believed they had proven to be stronger than their illness. ‘I learned to live with my heart disease. I know that I have some limitations, but I don’t want them to stop me from living my life’ (Interview 10). ‘I feel stronger and I also feel quite lucky [...] I have dealt with my illness and health problems. This allowed me to understand what is really important in life. Facing my illness and real health problems has allowed me to face serenely the futile problems of life that for many seem insurmountable’ (Interview 4). Some patients described the experience of the disease not as a compromised state of health, but as an aspect of their lives which they simply had to accept and that they can feel made them no different from their ‘healthy’ peers. ‘Because for us, it was a normal thing [...] because it was my life, unfortunately, and I had to live with this disease. I had to do my checks, how could I hide it? We talked about it and they listened to us and understood us’ (Interview 5). ‘I tend to live a normal life...I never wanted to be a burden to anybody because I tend to do a normal job, a normal life’ (Interview 7).

However, the subtheme ‘The difficulty of living with a heart condition’ also highlights the other side of the coin: the awareness of being affected by a chronic condition, which necessarily involves undergoing repetitive cardiac surgery that sometimes involves clinical implications. These situations can cause feelings of fear, discomfort, anger and uncertainty about the future: ‘At one point I really collapsed, I started to stop eating, I was totally in crisis.’ (Interview 12). ‘Huh, it annoyed me a little bit, because I saw other children running, riding a bike, and

instead I always felt tired. Even going to school, I got tired walking. They had to carry me in their arms and I was also ‘grown-up’ (Interview 2). ‘It was very tragic to live in this situation, it was a bit traumatic; in fact, after I collapsed psychologically ... on returning from the surgery ... and then my family doctor recommended a psychological therapy to follow ... fortunately, he directed me to a very good psychologist and still today after 26 years, we are in contact for this problem that I have, so it was definitely the coup de grâce’ (Interview 5).

### Theme two: Being a mother with CHD

The second theme explores the experiences of these women in relation to the meaning and perspectives of being mothers with CHD, and it emerged from four specific subthemes: (1) *desire for maternity*, (2) *victory*, (3) *fears* and (4) *relationship with children*. Surely, the motivation among the participants that conditioned and supported the experience of pregnancy and all of the challenges that it entails for a woman with CHD was the strong desire for motherhood, which was more enduring than the fears they experienced. ‘I always liked it; I always hoped to be a mom’ (Interview 4). ‘Sometimes I overcame even the doubt and uncertainty of being able to remain pregnant. About a child my thoughts were: What if I can’t do that?’ (Interview 7). This dynamic became more prevalent the more severe the disease was, which in some cases has led health professionals to advise against women with CHD to giving birth. ‘Back in Italy [after cardiac surgery] everyone excluded me from having children’ (Interview 5). ‘But it’s always been my wish. Honestly, I didn’t think much about it, even though the doctors didn’t really recommend it to me. I decided, and that’s what happened. Because you’re a little unaware when you’re young.’ (Interview 8).

In fact, the stories have shown that this experience has brought to light both positive and negative feelings for participants, but especially fears and uncertainties about the future, conditioned by the awareness that the presence of their disease could increase the risks and complications related to pregnancy, both for themselves and their children. However, pregnancy was seen by the patients interviewed as a challenge to be faced and overcome, almost a victory, due to their strong desires to be mothers. ‘I went on and I wanted the chance to have children; it was a full victory’ (Interview 5). ‘The most beautiful time of my life, in the sense that it was still a challenge [...] a feeling of victory. In fact, I wanted to call her Victoria, but her dad did not like it, but for me it was just a victory, it was my victory over my illness, over all the dreams I thought I could not achieve’ (Interview 8). Fuelled by doubts about their desired futures, the interviewed new mothers experienced the birth of an unexpected force within them that was fed by the child held in their arms. As warriors, they emerged victorious from the greatest battle of their lives: becoming a mother. ‘It means that we are warriors, that we always win, that we never stop and that we are stronger than the others who are actually fine’ (Interview 5).



From the analysis of the interviews, it emerged that one of the most common fears of these mothers is to transmit their disease to the child, and then force them to face the same difficulties of life because of heart disease. 'I was worried during pregnancy that he had a cardiac problem, heart disease, in fact he did have three fetal echocardiograms, because diseases such as mine are not hereditary but there is a higher percentage in the child if there is a parent who carries this disease [...] That was my concern; but then, already during pregnancy when I was told that he did not present problems, that his heart chambers and the flows were in place, I was very serene.' (Interview 1) 'I was afraid they'd have the same problem as me.' (Interview 9). Moreover, for participants, the fear of passing on the disease to the children was often followed by a feeling of anguish towards them, linked to the fear of not being able to raise their own child. 'I was afraid that something could happen to me but also afraid, and it was the strongest fear, to transmit them anything to the heart. I hope I live long enough for him.' (Interview 1). 'My biggest fear was—I've told myself—if anything happens to me who will take care of my son?' (Interview 4). 'I had sworn to myself that I would never have my operation again, and I did it because I wanted to see her grow' (Interview 12).

Being a parent can be one of the most difficult but rewarding challenges in life, and it is often influenced by one's own experience as a child. The patients interviewed, thinking back to their childhoods, made up of winding paths and obstacles to overcome, saw their parents as very apprehensive about them because of heart disease. From here, therefore, comes the awareness of their parental role and the way they relate with their children. 'I think I'm very present and very involved in her life, as my mother was in my life. However, I would like to avoid being—as she was sometimes—a bit intrusive; partially of course, because it is nice to know that there is someone at your side who is involved in your successes, who encourages you, supports you, that gives you many opportunities to do things to know, to travel. My parents, despite their apprehension, have made me make many experiences, so I would like to be present and have the opportunity to give so much and give him all the possibilities that I had, and even more, not in material terms' (Interview 1). 'Then I always hope to be well and to be what I have always thought a parent should be someone to rely on, from which to have encouragements' (Interview 8). 'In comparison to other mothers, I realize that I am much more present, indeed, perhaps even too much' (Interview 11). However, the severity of the mothers' pathology had sometimes created repercussions for their children's lives: 'The children have not lived it well; sometimes, they told me 'mum, please take care of yourself', especially now that they know that I need to have an operation again [...] they are worried' (Interview 1). 'My daughter is seen by a psychologist because a year and a half ago, she fell into anorexia and the psychologist who follows her says that she puts aside the thought of my illness and denies it, precisely because I realize that it is

something that she finds hard to care about' (Interview 9).

### Theme three: Don't be alone

The data illustrate the importance of "Don't be alone". The sharing of the difficulty, changes and management of illness could be the key to experiencing a good quality of life in spite of the numerous challenges faced by pregnant women with CHD. In fact, many mothers have testified that sharing their condition with other people had been fundamental in their ability to deal with it. In this respect, both family members and health professionals play a very important role during the hospitalisation and follow-up periods. In addition, peer support is also essential, especially from associations for people with CHD, because patients with the same pathology can engage each other on equal footing. This third main theme consists of three specific subthemes: (1) *family support*, (2) *social and association support*, and (3) *support from health personnel*.

Numerous pieces of literature have shown that the role of the informal caregiver (ie, the family member) is fundamental for the optimal management of chronic diseases. In addition, in the experiences of the interviewed mothers emerges the fact that the affection of the family, such as the parents and partner, is an enormous need, and its obtainment is strategic in allowing patients to face the daily challenges that CHD brings with it. The more you feel fragile, and weak, the more you need the support of people who love you. The mothers interviewed, on more than one occasion, expressed the need and desire to be protected, consoled and supported—to feel loved and welcomed despite the difficulties of the disease. Often, from the patients' stories emerged how much the family has been a pillar of support that allows them to overcome difficult moments, such as when they felt tired and unable to perform a task or overcome a surgical operation. 'My partner is very protective; he has been with me for three years and has not yet experienced the worst, darkest moments of my heart disease ... he has not witnessed an operation of this kind yet, and he is so protective that when I say, 'let's do this, let's do that,' he says, 'no, please rest a little more, do not exert yourself,' but he never treated me as a different person ... let's say that it is an established fact; the love he feels for me, has never made me feel different (Interview 10). 'My husband definitely helps me a lot [...] he always wanted me to live this thing in a normal and serene way, indeed sometimes my daughters said something, but he always tried to minimize the thing' (Interview 3). 'She has been a great mother, in the sense that she has always been there and has given me so much strength and help, even with the child, but so much, without ever giving me a hard time, I do not know how she did, but my mother has never made me feel sick, even now as a mother I wonder how' (Interview 12).

In addition, many of the mothers interviewed claimed to have found support from people who live with their same clinical condition because it allows them to compare



different experiences, share suggestions or help, and feel useful to someone or find in other stories the strength to achieve goals, all of which seem to have an important therapeutic effect. 'In the sense that, I don't know... the fact that I still ... well, I volunteer in both the adult and children's ward with those who have heart disease like mine and, perhaps, the fact that I can help others, talk to them, exchange ideas, has certainly helped me, has calmed me down' (Interview 3).

Finally, the accounts also highlight the importance of empathic relationships with healthcare personnel. Doctors, nurses, psychologists, and so on, all become the strongest allies during one of the most delicate and vulnerable moments of the participants' lives. They often seem to be the only ones who understand and share the state of mind and emotional situation that the mothers interviewed have experienced, and this has generated the feeling of being protected and comforted and, therefore, the strength to face the difficulties. 'I was so calm because I trusted my cardiologist' (Interview 2). 'Some girls came to visit me [...] they helped me a lot' (Interview 7). 'I must say that also the doctors gave me strength, because I found special ones on my path: Dr. F., who was like a dad, even Dr. M., Dr. C. This is, really, a family' (Interview 12).

## DISCUSSION

To the best of our knowledge, this is the first study aimed at the in-depth exploration of the perspectives of Italian women with CHD who have experienced pregnancy and motherhood. The adopted phenomenological methodology is pivotal for starting to bridge this knowledge gap and for supporting healthcare providers in the design, test and implementation of specific intervention programme. In fact, our results contribute to the understanding of the little-known challenges endured by women with CHD who desire and have experienced pregnancy despite the high risks and complications caused by their illness.<sup>29</sup> Results of this study could be pivotal for cultivating a tailored and theory-grounded healthcare delivery system for the mothers with CHD as well as for their children and whole family.

An innovative point of view of mothers with CHD was given by the first main theme (*Theme one: Being a woman with CHD*), where the participants emphasised their feeling of being 'women' before being mothers, with both positive and negative feelings associated with their disease. In fact, pregnant women with chronic disease generally attribute to their pregnancy the role of allowing them to return to normal life.<sup>30</sup> They describe pregnancy as a balancing act between the fantasy of being normal and the reality of having a chronic condition.<sup>30</sup> Despite this, in our study, women with CHD had learnt to live with their illness, accepting their condition. These study results suggest that the interviewed women are aware of their clinical status, unlike previous descriptions for women with other chronic conditions in which the women were observed to underestimate their condition,<sup>31</sup> almost minimising the

risks of the disease.<sup>32</sup> In many interviews, women nicknamed themselves 'warrior women', as they were able to face both the joyfulness and difficulties during their lives. They also identified their disease as an integral part of their lives. This is certainly the first peculiarity of this population: These women learnt to live with their disease by accepting it, almost considering their disease as normal in relation to their perceived health and quality of life. Both perceived health and quality of life in adult patients with CHD have already been investigated.<sup>33</sup> For instance, Kovacs *et al*<sup>34</sup> carried out a thorough review of the literature to synthesise knowledge about the emotional regulation of adults with CHD, describing the mechanisms that could lead to a psychological maladjustment influencing overall quality of life.

Overall, women in our study—even those with moderate or severe CHD—strongly desired motherhood despite the significant health-related risks associated with their clinical condition (*Theme two: Being a mother with CHD*). Motherhood was often experienced as a 'victory' over the difficulties they had experienced because of their disease.<sup>32</sup> As previously described, the strong desire related to motherhood is the most plausible trigger that conditioned their experiences related to pregnancy.<sup>20</sup> The mechanism emerging from the described desire in the cases of our interviewed mothers with CHD seems to be similar to the mechanism described in mothers with type 1 diabetes mellitus, which is characterised by an overwhelming positive change, constant learning and a reconstruction of self.<sup>35</sup>

Finally, the support given by healthcare providers, family members and people with the same conditions (ie, peers) was represented by the third theme (*Don't be alone*), inasmuch as support plays a very important role during the hospitalisation and follow-up periods.<sup>33</sup> Mothers with CHD expressed that sharing their condition, fears and thoughts with other people was fundamental to their ability to face the burden of their disease during pregnancy and early motherhood. This aspect has been extensively described in the literature about diverse chronic conditions.<sup>35</sup>

## Strength and limitations

This study presents some strengths and limitations. The main strength is the innovative idea of the research that opens up an underinvestigated scenario. Another strength is provided by the use of IPA methodology for overviewing the lived experiences of women with CHD. Overall, our results have not exhausted the knowledge available on the meaning of being a mother with CHD, but they have produced an initial exploration of the study phenomenon, representing a first attempt to incentivise research on the peculiarities and needs of female patients with CHD during pregnancy and motherhood. However, our findings are based on the reflections of 12 mothers with CHD about their own experiences; for this reason, caution is needed in the context of generalising our results. Although efforts were made to recruit



a homogenous sample, the mothers differed in aspects such as their age and the number of children they had. All of these differences could influence the themes that emerged from the experiences. Furthermore, it is also possible that the participants were more willing to tell their stories than others, which suggests they possessed better psychological adjustments in regard to their clinical conditions than those who declined to participate. Despite these limitations, it is evident from the resulting themes that commonalities existed across narratives, providing valuable insight into the experiences of mothers with CHD.

### Future research

As described in the study's results, the experiences of pregnancy in women with CHD should be the starting point for shaping personalised support programme. Moreover, the main themes that emerged could represent a real theoretical framework that has to be deeply investigated via empirical research. For example, future research should continue to take into consideration the perspectives of mothers with CHD, as pregnancy in patients with CHD represents one of the most important contemporary challenges for experts in the field, in which the multidisciplinary management of these women's conditions is imperative.<sup>17</sup> Nevertheless, many aspects in this regard are still unexplored, and researchers need to devise more engaging, personalised methodological approaches to elicit the lived experiences of women with CHD.

Specifically, research aimed to deepen the maternal experiences with quantitative studies could be very interesting, as it could describe some of the outcomes (eg, quality of life, health needs, self-care and mutuality) with cross-sectional or longitudinal observational designs. Further, the emerged themes could represent an initial framework for implementing theory-grounded educational strategies to improve self-care, engagement and quality of life. They could also provide guidance to operationalise the described experiences into items for future cross-national surveys. In this context, there is further need for research that develops specific tools for the measurement of each experiential theme identified by the present study. Deepening research on which aspects, such as mutuality or self-care, could influence or predict the clinical outcomes of these women<sup>36–38</sup> would have an important impact on daily clinical practice.

Finally, future studies should also consider the experience of healthcare providers when dealing with this patient population or the lived experiences of patients with CHD during the paternal experience. Because sex-related differences among various populations are a field of research that has recently grown,<sup>39–41</sup> we imagine substantial differences in the parenting experience between mothers and fathers with CHD. Thus, another interesting study would describe the impact of a mother's CHD diagnosis on married couples<sup>42</sup> and on the experiences of their child.

### CONCLUSIONS

This study explored the experiences of women with CHD during pregnancy and early motherhood using the IPA methodology. Three main themes emerged from our interviews with mothers with CHD, and they reveal the many challenges this population faces alongside the important impact and burden the disease has on their daily lives. Further investigations are needed to better define which healthcare approaches could be strategic in supporting women with CHD throughout their experience of pregnancy and creating specific intervention programme for this population. Results from this study could be used by both healthcare providers and researchers. Healthcare providers can use our results to enrich their knowledge about the in-depth experiences of women with CHD during pregnancy and early motherhood. Researchers can use the emerged themes as an initial framework to deepen knowledge in this field.

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### REFERENCES

- 1 Bouma BJ, Mulder BJM. Changing landscape of congenital heart disease. *Circ Res* 2017;120:908–22.
- 2 Marelli AJ, Mackie AS, Ionescu-Iltu R, et al. Congenital heart disease in the general population: changing prevalence and age distribution. *Circulation* 2007;115:163–72.
- 3 Warnes CA, Liberthson R, Danielson GK, et al. Task force 1: the changing profile of congenital heart disease in adult life. *J Am Coll Cardiol* 2001;37:1170–5.
- 4 Capozzi G, Caputo S, Pizzuti R, et al. Congenital heart disease in live-born children: incidence, distribution, and yearly changes in the Campania region. *J Cardiovasc Med* 2008;9:368–74.
- 5 Calzolari E, Garani G, Cocchi G, et al. Congenital heart defects: 15 years of experience of the Emilia-Romagna registry (Italy). *Eur J Epidemiol* 2003;18:773–80.
- 6 Favilli S, Santoro G, Ballo P, et al. Prevalence and clinical characteristics of adult patients with congenital heart disease in Tuscany. *J Cardiovasc Med* 2012;13:805–9.
- 7 Engelfriet P, Boersma E, Oechslin E, et al. The spectrum of adult congenital heart disease in Europe: Morbidity and mortality in a



- year follow-up period - The Euro Heart Survey on adult congenital heart disease. *Eur Heart J* 2005;26:2325-33.
- 8 Flocco SF, Giamberti A, Micheletti A, et al. The effects of a standardized set of educational interventions on the health perception of adolescents with congenital heart disease (transition model): preliminary results of a quasi-experimental study. *G Ital Cardiol* 2018;19:386-93.
  - 9 Flocco SF, Dellafiore F, Caruso R, et al. Improving health perception through a transition care model for adolescents with congenital heart disease. *J Cardiovasc Med* 2019;20:253-60.
  - 10 Dellafiore F, Caruso R, Arrigoni C, et al. Lifestyles and determinants of perceived health in Italian grown-up/adult congenital heart patients: a cross-sectional and pan-national survey. *BMJ Open* 2019;9:e030917.
  - 11 Opotowsky AR, Siddiqi OK, D'Souza B, et al. Maternal cardiovascular events during childbirth among women with congenital heart disease. *Heart* 2012;98:145-51.
  - 12 Regitz-Zagrosek V, Roos-Hesselink JW, Bauersachs J, et al. 2018 ESC guidelines for the management of cardiovascular diseases during pregnancy. *Eur Heart J* 2018;39:3165-241.
  - 13 Bianca I, Geraci G, Gulizia MM, et al. Consensus document of the Italian association of hospital cardiologists (ANMCO), Italian Society of pediatric cardiology (SICP), and Italian Society of gynaecologists and obstetrics (SIGO): pregnancy and congenital heart diseases. *Eur Heart J Suppl* 2017;19:D256-92.
  - 14 Canobbio MM, Warnes CA, Aboulhosn J, et al. Management of pregnancy in patients with complex congenital heart disease: a scientific statement for healthcare professionals from the American heart association. *Circulation* 2017;135:e50-87.
  - 15 Song YB, Park SW, Kim JH, et al. Outcomes of pregnancy in women with congenital heart disease: a single center experience in Korea. *J Korean Med Sci* 2008;23:808-13.
  - 16 Niwa K. Adult congenital heart disease with pregnancy. *Korean Circ J* 2018;48:251.
  - 17 Ntiloudi D, Zegkos T, Koutsakis A, et al. Pregnancy in patients with congenital heart disease: a contemporary challenge. *Cardiol Rev* 2017;25:326-30.
  - 18 Flocco SF, Caruso R, Dellafiore F, et al. The effect of the transition care model on health perception among adolescents with congenital heart disease: a quasi-experimental study]. *G Ital Cardiol* 2018;19:386-93.
  - 19 Claessens P, Moons P, de Casterlé BD, et al. What does it mean to live with a congenital heart disease? A qualitative study on the lived experiences of adult patients. *Eur J Cardiovasc Nurs* 2005;4:3-10.
  - 20 Ngu K, Hay M, Menahem S. Case studies of the perceptions of women with high risk congenital heart disease successfully completing a pregnancy. *Heart, Lung and Circulation* 2014;23:811-7.
  - 21 Smith JA, Flower P, Larkin M. Interpretative phenomenological analysis: theory, method and research. *Qual Res Psychol* 2009;6:346-7.
  - 22 O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research. *Academic Medicine* 2014;89:1245-51.
  - 23 Smith JA. Interpretative phenomenological analysis: getting at lived experience. *J Posit Psychol* 2017;12:303-4.
  - 24 Whiting LS. Semi-structured interviews: guidance for novice researchers. *Nurs Stand* 2008;22:35-40.
  - 25 Corbin JM, Strauss AL. *Basics of Qualitative Research : Techniques and Procedures for Developing Grounded Theory*. Thousand Oaks: Sage, 1998.
  - 26 Crowe M, Inder M, Porter R. Conducting qualitative research in mental health: thematic and content analyses. *Aust N Z J Psychiatry* 2015;49:616-23.
  - 27 Sandelowski M. Focus on research methods-whatever happened to qualitative description? *Res Nurs Heal* 2000;23:334-40.
  - 28 van Nes F, Abma T, Jonsson H, et al. Language differences in qualitative research: is meaning lost in translation? *Eur J Ageing* 2010;7:313-6.
  - 29 Ntiloudi D, Giannakoulas G. Pregnancy still contraindicated in pulmonary arterial hypertension related to congenital heart disease: true or false? *Eur J Prev Cardiol* 2019;204748731882534.
  - 30 Tyer-Viola LA, Lopez RP. Pregnancy with chronic illness. *Journal of Obstetric, Gynecologic & Neonatal Nursing* 2014;43:25-37.
  - 31 Sabanayagam A, Briston D, Zaidi AN. Attitudes and perceptions of pregnant women with CHD: results of a single-site survey. *Cardiol Young* 2017;27:1257-64.
  - 32 Ngu K, Hay M, Menahem S. Perceptions and motivations of an Australian cohort of women with or without congenital heart disease proceeding to pregnancy. *Int J Gynaecol Obstet* 2014;126:252-5.
  - 33 Gantt LT. Growing up heartsick: the experiences of young women with congenital heart disease. *Health Care Women Int* 1992;13:241-8.
  - 34 Kovacs AH, Sears SF, Saidi AS. Biopsychosocial experiences of adults with congenital heart disease: review of the literature. *Am Heart J* 2005;150:193-201.
  - 35 Sparud-Lundin C, Berg M. Extraordinary exposed in early motherhood - a qualitative study exploring experiences of mothers with type 1 diabetes. *BMC Womens Health* 2011;11:10.
  - 36 Vellone E, Chung ML, Alvaro R, et al. The influence of Mutuality on self-care in heart failure patients and caregivers: a Dyadic analysis. *J Fam Nurs* 2018;24:563-84.
  - 37 Vellone E, Dellafiore F, Chung ML, et al. Mutuality and self-care in heart failure patient and caregiver dyads. *Eur J Cardiovasc Nurs* 2018;17:467-8.
  - 38 Dellafiore F, Borella A, Magon A, et al. Descriptive pilot study on self-care and daily living activities in Italian patients with heart failure: what are the criticalities? *Ric e Prat* 2018;34.
  - 39 Caruso R, Arrigoni C, Magon A, et al. Health determinants in Italian type 2 diabetes mellitus (T2DM) patients: a critical gender differences analysis. *J Res Gen Stud* 2017;7:93-108.
  - 40 Dellafiore F, Conte G, Baroni I, et al. Gender differences in heart failure self-care behaviors: do we know enough? *Minerva Med* 2018;109:401-3.
  - 41 Dellafiore F, Arrigoni C, Pittella F, et al. Paradox of self-care gender differences among Italian patients with chronic heart failure: findings from a real-world cross-sectional study. *BMJ Open* 2018;8:e021966.
  - 42 Dellafiore F, Rosa D, Pittella F, et al. The impact of type 2 diabetes diagnosis on married couples. *J Diabetes Nurs* 2018;22.