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Challenges of inclusive schooling for children and adolescents with congenital heart disease: A phenomenological study

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Abstract

Educational attainment is closely associated with health. The objective is to explore the extent to which children and adolescents with congenital heart disease (CHD) are afforded the same educational and socialization opportunities as their healthy peers. We used a qualitative phenomenological design with convenience sampling. Data gathered 27 semistructured interviews: children with CHD ($n = 9$), parents ($n = 10$), and professionals ($n = 8$) in Catalonia, Spain. Interview transcripts were coded using the constant comparative method and analyzed using ATLAS.ti software. The analysis revealed three themes describing the experience of schooling for children with CHD: (1) Empowering and enabling a child with CHD to achieve academically and engage socially is a challenge for parents; (2) Teachers lack the resources and specific skills necessary to meet the diversity needs of children with CHD; (3) Parents and teachers have low expectations regarding the academic achievement of a child with CHD. Further application of the constant comparison method yielded a core theme: (4) Children with CHD experience exclusion from peer group social learning activities. Further efforts are needed for more effective collaboration and coordination between educational

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and health professionals to provide support for teachers and families and enable children to be better integrated within schools.

KEYWORDS
children, complex health condition, congenital heart disease, family

1 | INTRODUCTION

Congenital heart disease (CHD) is the most common class of major congenital malformation (Van der Linde et al., 2011). Total CHD birth prevalence is around 9 per 1000 live births, although regional differences have been reported: 9.3 per 1000 live births in Asia, 8.2 in Europe, 6.9 in North America, 6.5 in South America, and 6.2 in Oceania (Van der Linde et al., 2011).

Since 1953, and the first successful repair of a congenital heart defect using cardiopulmonary bypass, the possibility of early diagnosis and effective treatment (Triedman & Newburger, 2016) has led to significant improvements in survival rates among children with CHD (Marelli et al., 2014). Indeed, life expectancy for these patients has increased considerably in recent decades (Moons et al., 2010), and over 90% of children born with a congenital heart defect are now expected to survive into adulthood (Mulder, 2012). However, these children usually remain medically fragile with specific and significant care needs (Dewan & Cohen, 2013).

Because academic achievement is closely associated with physical and mental well-being and healthy behaviors (Scharoun-Lee et al., 2009), children with CHD often do worse at school in comparison with their healthy peers (Lum et al., 2019). One of the factors that undermines their achievement is illness-related absence from school (Nousi & Christou, 2010). Their ability to learn is also affected by the physical and psychological impact of their condition (Mccusker et al., 2013), which can leave them fearful of the future (Birks et al., 2007) and distanced from peers as a result of missing school and not being able to participate in certain activities (Birks et al., 2007). Accordingly, children with CHD are generally at greater risk of psychosocial problems such as low self-esteem, higher levels of anxiety and depression, and poor social and behavioral adjustment (Casey et al., 1996).

Children with CHD pose a challenge for the education system (Farr et al., 2018; Kang et al., 2016; Lawley et al., 2019; McMurray et al., 2001; Violant et al., 2012; Wray et al., 2018), as well as for their classroom teachers and other school professionals (Seki et al., 2017). School provides children and adolescents with opportunities to develop academically, socially, emotionally, and physically (Lum et al., 2017), and consequently, schooling differences are a major component of differences in physical and mental health (Adams, 2002). Indeed, various studies have shown that educational attainment is strongly associated with better health-related outcomes (Scharoun-Lee et al., 2009) and that people with more schooling have less morbidity and tend to live longer (Whalley, 2001).

The formal education that schooling entails is a facilitating factor of social learning (Gweon, 2021) that aims at the educational achievement of students (Scharoun-Lee et al., 2009). An important part of human behavior is learned by modeling what is observed in others (Bandura, 1977). From this theory, in the school context, children acquire knowledge through social learning by modelling the behavior of their teachers and peers. Consequently, adjusting to the school environment is of paramount importance to children's development.

Although children and adolescents with CHD spend much of their time in school, only a few studies have examined their school-related adjustment (Im et al., 2017). Further research is, therefore, warranted to explore how children with CHD, as well as their parents and the education professionals who are their role models, perceive the school experience as part of the social learning process.

This would help to identify areas in need of improvement and provide a basis for designing interventions aimed at empowering these children towards academic and personal achievement, better health results (Scharoun-Lee et al., 2009), lower morbidity, and longer life expectancy (Whalley, 2001).

When it comes to meeting the needs of children with CHD in relation to schooling and, therefore, social learning, it is important to consider three key aspects: (1) professionals, who must have the training needed to fulfill their pedagogical role, whether in schools or hospital classrooms (González-González et al., 2021); (2) parents, who have a central role to play in supporting their child's schooling and socialization (Dalir et al., 2020); and (3) the children themselves, with their specific individual and social needs (Farr et al., 2018; Violant et al., 2012). Consequently, the aim of this study was to explore the views of children, parents, and professionals regarding the extent to which children with CHD are afforded the same educational and social opportunities as their healthy peers.

2 | METHODS

This was a qualitative study informed by phenomenology. A theoretical review was conducted to build a preliminary theoretical framework that gave us a baseline of the needs of this population. We chose this inductive approach as one that allowed us to describe and understand the lived experience of participants and to identify key concepts in their personal narratives (Morse, 2012).

2.1 | Setting

Convenience sampling was used to recruit three kinds of informants: school-age children with CHD, parents with school-age children with CHD, and professionals (four teachers, one school principal, one physical education teacher, and two educational psychologists); who, through their work, had come into contact with children with CHD (see Tables 1–3) in three provinces of Catalonia, Spain (Barcelona, Lerida, and Tarragona). Due to the nature of the sample, some parents and professionals participated independently without their child/student. This was done with the aim of achieving maximum variation in terms of participants and contexts (Seidman, 2013). Sampling ended when theoretical saturation was reached (Strauss & Corbin, 2002) and interviews yielded no new information. Regarding the homogeneity of the sample, efforts were made to ensure that there was representativeness. Nonetheless, there is one main difference between the children's cohort and the parents and professionals' cohorts: the lived experience. Children live with CHD while parents and professionals do not.

2.2 | Data collection

Data were collected through semistructured interviews, a suitable approach for gathering people's views regarding complex and emotionally sensitive topics (Astedt-Kursi & Heikkinen, 1994), such as CHD. The use of semistructured interviews also means that questions or prompts can be adapted according to the verbal and nonverbal responses of informants (Polit & Beck, 2010). Following the recommendations of Kallio et al. (2016), we first consulted experts in the field (including, in this case, parents and teachers) to draw up a separate interview guide for each of the three kinds of informants: children with CHD, parents of a child with CHD, and education professionals (see Table 4).

The following inclusion criteria were applied: (1) Children with CHD: Participants aged 6–12 with sufficient cognitive ability to understand the purpose of the study and to read, understand, and sign the consent form; (2) Parents of a child with CHD: Participants must be the parent or guardian of a child with a heart disease, and they had to be willing to answer the family interview portion; (3) Professionals: Participants must be working (currently or in the past) in the school environment with a child diagnosed with a heart disease. Access to participants was through AACIC, an association in

TABLE 1 Characteristics of interviewed children with congenital heart disease (CHD).

Participant child (PC)	Age	Sex	School year	Repeating year	Siblings
PC1	11	Female	Primary 6	No	Yes
PC2	8	Female	Primary 2	No	Not
PC3	10	Male	Primary 5	No	Yes
PC4	7	Male	Primary 1	No	Yes
PC5	9	Female	Primary 4	No	Yes
PC6	7	Male	Primary 2	No	Yes
PC7	12	Male	Primary 6	No	Yes
PC8	8	Female	Primary 3	No	Yes
PC9	6	Female	Primary 1	No	Yes

TABLE 2 Characteristics of interviewed families.

Participant family (PF)	Attended by	Mother's age	Father's age	Mother's education/ profession	Father's education/ profession
PF1	Mother/father	39	40	Pharmacy/pharmaceutical	Third year of secondary school/ Iberia airlines
PF2	Mother/father	36	41	Primary school/check-out operator	Primary school/tax inspector
PF3	Mother/father	38	40	Library sciences/librarian	Economist/economics teacher
PF4	Mother/father	35	43	Auxiliary nurse	Clerk
PF5	Mother/father	38	39	Public relations/fashion salesperson	Economist/business consultant
PF6	Mother/father	54	54	Housewife	Mid-level business management
PF7	Mother	40	47	Secondary school/civil servant	Primary school/ business-workshop
PF8	Mother/father	46	50	Secondary school-tourism studies/shop assistance	Primary school/waiter
PF9	Mother	37	40	Primary school/real estate agent	Primary school/ machinist
PF10	Mother	48	49	Education/teacher	Philosophy/head of department

Catalonia (north-east Spain) whose mission is to provide advice and support to children with CHD, their families, and related professionals. Potential participants were initially contacted by telephone to inform them about the nature of the study and to request their involvement. Those who agreed were then invited for interview in an easily accessible location, with informed consent (adults) and assent (children) being obtained before any data collection. The interviews were conducted by different members of the research team, none of whom had had any prior contact with participants.

TABLE 3 Characteristics of interviewed professionals.

Participant professional (PP)	Age	Sex	Year taught	Academic training	Job
PP1	41	Female	Preschool 4	Teaching degree	Tutor/teacher
PP2	56	Female	Primary 1	Teaching degree	Tutor/teacher
PP3	46	Male	Primary 6	Teaching degree	Tutor/teacher
PP4	52	Female	Primary 4	Teaching degree	Tutor/teacher
PP5	54	Female	Primary	Clinical psychologist	Educational psychologist
PP6	45	Male	Primary	Teaching degree	Physical education
PP7	45	Male	Primary	Teaching degree	School principal
PP8	42	Female	Primary	Clinical psychologist	Educational psychology advisory team

TABLE 4 Aspects covered in the interviews with children with CHD, families, and professionals.

Sample	Aspects covered in the interviews	Sample of interview questions
Children with CHD	1. Self-concept 2. Personal resources (cognitive and behavioral) 3. Motivation 4. Patient role 5. Adherence to treatment 6. Cooping styles 7. Social relationships 8. Perception towards school 9. Extracurricular activities 10. External support	What do you like most about yourself? What is the hardest thing for you to do? If you met a genie or a fairy, what three wishes would you ask? Who in your family do you spend the most time with? Do you listen to what the doctors tell you to do? How do you act when you don't feel well? Are you happy with what you learn in school? Do you do extracurriculars after school? With whom do you do the extracurriculars?
Families	1. Needs, feelings, and expectations of the family 2. Needs of the child with CHD	With the knowledge you now have about the disease, how do you envision the future of your child? How is your child's social life?
Professionals	1. Social relationships 2. Educational resources (external support)	Do you think that children with CHD influence the class dynamics (work rate, peer coexistence, etc.)? Are the teaching resources used with children with CHD the same as the resources used with the rest of the students? If not, how are they adapted?

Abbreviation: CHD, congenital heart disease.

2.3 | Data analysis

All interviews were audiotaped and transcribed verbatim. With the aim of extracting as much information as possible from the transcripts, we applied the constant comparative method, an analytic approach informed by grounded theory (Astedt-Kursi & Heikkinen, 1994; Strauss & Corbin, 2002). Following Strauss and Corbin (2002), we began with the open or substantive coding of data, linking fragments of the participants' discourse to coding labels. This was followed by focused coding to identify the most frequently occurring codes, thus enabling us to draw up a provisional set of emergent categories and to describe their properties and dimensions (axial coding). The application of a coding paradigm throughout the analytic process allowed us to establish relationships between

categories as part of the process of selective coding. This was then complemented by a literature review to contextualize and interpret the findings and to develop the theoretical narrative that is presented in Section 3. A series of code, theoretical, operational (Charmaz, 2006) and bibliographic memos were also generated to support the traceability of the analysis. The data analysis was carried out in an integrated way, selecting participants of the three typologies based on the criterion of maximum variability and integrated into the same analytical process.

Regarding rigor, several strategies were used to achieve validity and reliability based on the criteria described by Guba (1981). The use of work standards and the ATLAS.ti software (as operative support) helped to ensure a systematic approach throughout the analytic process. Furthermore, all researchers involved in analyzing the data kept a reflexive journal so as to allow an internal audit of the process and ensure the confirmability of results. To support the credibility of our interpretation of the data, the results are illustrated with verbatim quotations from the interview transcripts. With respect to transferability, we describe the sampling context (see Tables 1–3) and do not assume that our findings are generalizable to other settings.

3 | RESULTS

A total of 27 interviews were conducted, involving 9 children with CHD, 1 or both parents from 10 families with a child with CHD, and 8 education professionals (which included both teachers and other specialists). Note that the nine children came from different families to those in which we interviewed parents.

The analysis of interview transcripts revealed three main themes that describe the characteristics of the social learning carried out in the school environment by the child with CHD in the narratives of the various informants: (1) Empowering and enabling a child with CHD to achieve academically and engage socially is a challenge for parents; (2) Teachers lack the resources and specific skills necessary to meet the diversity needs of children with CHD; and (3) Parents and teachers have low expectations regarding the academic achievement of a child with CHD.

Further application of the constant comparative method revealed a core theme (see Figure 1) that gives response to whether the social learning opportunities are the same as in the case of their peers; (4) Children with CHD experience exclusion from peer group social learning activities.

3.1 | Empowering and enabling a child with CHD to achieve academically and engage socially is a challenge for parents

Parents see their child with CHD as unable to do things that other children do. These functional limitations, which were highlighted in the study by Farr et al. (2018), can leave these children feeling less capable than others, undermining their self-esteem and creating a sense of insecurity.

> You see him as a normal child, but who can't do certain things. A boy in class who has his limitations when it comes to physical exertion, but that's it (Parent 3).

> I don't want to give it too much importance, but I know he often feels less capable, because of people's attitudes, and because he sometimes lets things slip (Parent 4).

> What I see is that there are times when he lacks self-esteem. Maybe he feels more insecure (Parent 6).

Ahn and Lee (2016) found that parenting behaviors influenced the self-concept of adolescents with chronic illness. Conversely, research suggests that adolescents with CHD who have adequate parental support are less

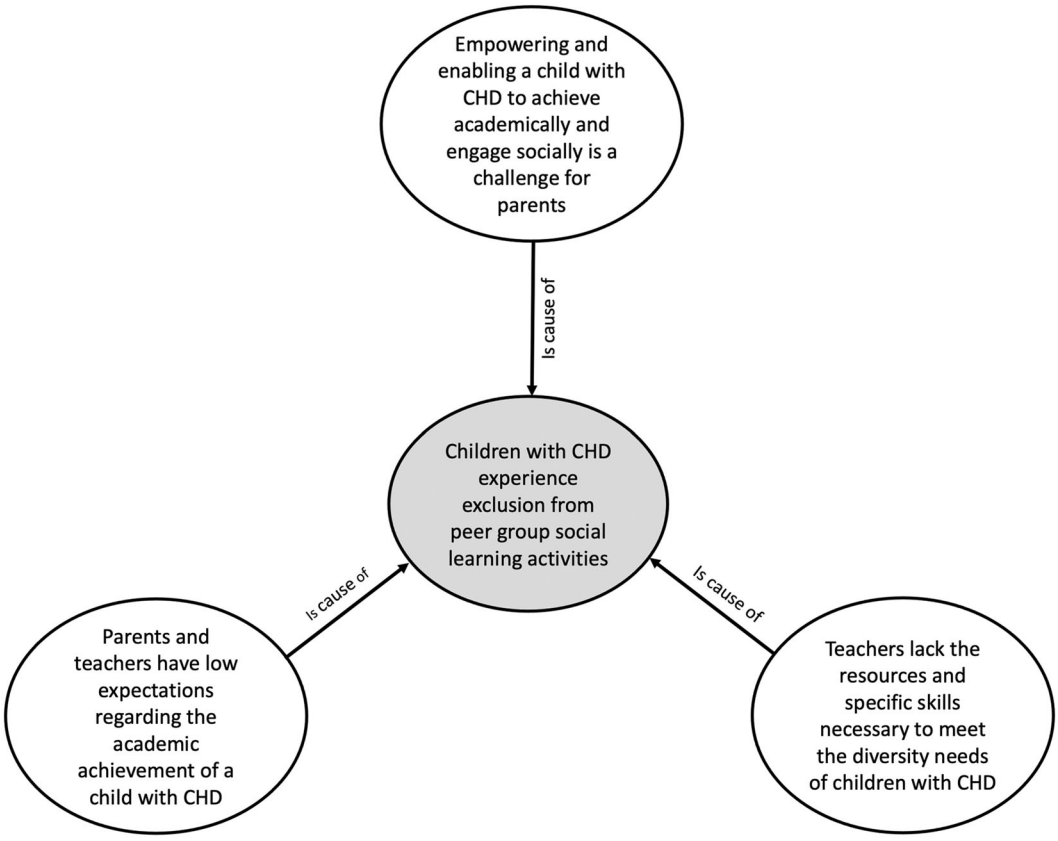

FIGURE 1 Core category "Children with CHD experience exclusion from peer group social learning activities". CHD, congenital heart disease.

likely to report depressive symptoms and feelings of loneliness (Vanhalst et al., 2013). The self-concept is a complex and dynamic system of learned beliefs that an individual holds to be true about him or herself (Purkey, 1970), and these beliefs are formed especially in response to environmental reinforcements and significant others (Shavelson et al., 1976).

> Parents tend to avoid social activities that draw attention to his or her differences, because they do not want their child with CHD to feel less capable. But you often stop him from doing things (Parent 3).

> You try to get him to lead a more passive life (Parent 5).

> But we haven't felt the need to make him do things. We have not been especially demanding when it comes to activities outside school (Parent 4).

However, as Immelt points out (Immelt, 2006), participation in age-appropriate tasks and activities is essential for children's well-being and the development of self-esteem. According to Violant et al. (2012), the relationships that children with CHD establish with peers depend more on the child's personality and social skills than on the

disease itself. In this respect, it is notable that some of the parents we interviewed looked favorably on their child's ability to hide his or her limitations from others, even seeing it as a sign capability.

> He's a boy with a strong sense of pride. If he sees that he might end up feeling less capable in a certain situation, then he won't go (Parent 4).

As Evans et al. (2008) argue, however, it is important to create an environment in which children can develop a healthy body image as the foundation of a positive and balanced sense of self, and thus of their self-esteem.

In summary, parents believe that their children have fewer opportunities in school. Nevertheless, they believe that it is positive to let children stop whatever activity they are performing when feeling tired or less capable.

3.2 | Teachers lack the resources and specific skills necessary to meet the diversity needs of children with CHD

The primary focus for teachers is on working to ensure that children with CHD do not fall behind academically. Although they considered that the school environment and the range of available materials allowed them to adapt their teaching accordingly, they also felt they lacked training and time in relation to promoting these children's communication skills and socialization.

> You focus on them not falling behind academically (Teacher 7).

> There's a lot of material, and educational publishers, where you can get ideas. We have books for primary year 3 that are easier if we need to adapt some of what we teach. I think the physical environment (the infrastructure) is good, it's more than sufficient to enable them to develop and achieve (Teacher 2).

> But communication with the other children, socialization, that is not something we spend much time on, and neither is it something we are well informed about (Teacher 7).

This is important because research suggests (Lee et al., 2019) that the well-being of adolescents with chronic illness can be enhanced by improving peer relationships. Among the parents and children with CHD we interviewed, there was a sense that not enough was being done to adapt learning activities so that their child could take part alongside peers. This was especially evident in relation to physical activities and sport.

> There are several activities they've let him do, when really he shouldn't (Parent 3).

> The teacher didn't think about changing the activity a bit so that I could join in (Child 5).

> They just see him as a boy with physical problems, and that's that. They do not look beyond that. It's like, OK, so he won't do sport (Parent 3).

Various studies have similarly identified a general lack of flexibility in the school syllabus, particularly with regard to sport, such that the needs of children with CHD (Ruggiero et al., 2018).

One of the issues raised by teachers concerned their lack of specific knowledge about the nature of a child's illness, and this generated a sense of fear and insecurity regarding whether they would know what to do in the event of an emergency.

> We do the best we can, but we all have our limitations [...] or when you need to accompany her to the toilet. She has a tendency to wander off. Someone always needs to go with her, because otherwise she will wander off around the school and who knows where she will end up. (Teacher 2).

> I do not know a thing about this topic. You know about heart attacks, in older people, adults, but not with children. It's a learning curve, I for one am learning things (Teacher 7).

> She's really open with everybody. She does not see the danger (Teacher 2).

> The teacher last year was scared, she didn't know whether the girl might suddenly die. That's how it is, the not knowing (Teacher 7).

They all agreed that there was a lack of specialist training and information aimed at them. Giroux et al. (2019) have previously suggested that a lack of knowledge among teachers regarding the care needs of children with chronic illness is a barrier to their school inclusion.

Some teachers said they had occasionally had help through an association, a hospital or a primary care center. Overall, however, it appeared that the education system, in general, struggled to support teachers who had a child with special health care needs in their class, this despite the fact that studies carried out in developed countries suggest that between 13% and 19% of children fall into this group (Bramlett et al., 2009).

> The team came and gave us some information. They asked us how we were doing and said they would assign a primary care nurse to places where there were problems of this kind. There's no sign of the nurse so far. That was back in October, so I guess there's red tape involved, but I think the will is there (Teacher 2).

> It was only after the mother joined the association that we started to get advice (Teacher 6).

> But when we heard about the association, we called them straightaway, and they came to talk to us. One of the special needs teachers did a short course and people from the association were there. That was the first contact we had, and they explained that they visited schools and gave free talks to parents. We called them and they've been two or three times to the school, and that's how we got some information (Teacher 7).

The difficulties teachers described in relation to accessing information and their fears about the child with CHD are also a consequence of a lack of connection and trust between parents and school staff. Professionals report that some parents show little interest perceived little interest in their child's condition on the part of teachers, while teachers said that families either did not provide them with information or even hid things from them, at times for fear of rejection.

> No, because they do not ask me what's wrong with my boy. There's no sense of being together in this... but neither have we opened up (Teacher 3).

> At the beginning, when the girl started here, we weren't told anything or given a report about what was wrong with her (Teacher 7).

> You only knew because you live in the same town and you've heard through word of mouth that they had to operate on her. Because up until now his mother had always said he was fine, there was no mention of his difficulties being related to a heart problem (Teacher 6).

> The mother was worried at first because she thought we did not want to have her [the child]. We told her [the mother] that it was in case something happened to the girl. So, then she told us about if her lips turned blue… Because we did not know, if something happened to her at some point, whether we should take her to the primary care center, which is next door, or call the mother or take her to the hospital. Now we do have all the information we need (Teacher 7).

> I do not know if they would know what to do in the event of an emergency (Parent 4).

> In an emergency, the teachers would phone us (Parent 3).

> It's only this year that I've been aware of the boy's problem, because up until now nobody had told me anything, that I had to keep an eye on him, that he must not overdo it because of his heart problems (Parent 2).

Situations of this kind are one of the ways through which individuals with chronic illness may come to experience social stigma (Nejatisafa et al., 2017), which then impacts behavior and their mental and physical health (Perry et al., 2010). A lack of communication between parents and teachers can also lead both parties to fear what might happen in the event that the child experiences a health emergency in the classroom.

In summary, professionals focus on ensuring that children with CHD do not develop academic delays. They believe that: (a) they lack time to foster communication and socialization skills and (b) they lack specialized training (related to the disease, what to do in an emergency, etc.) This generates fear and insecurity. On the other hand, they feel that there is mistrust between them and parents. Parents report that (a) professionals do not do enough to adapt to the needs of their children regarding participation with peers, learning activities, and sports activities and (b) there is a lack of interest from teachers.

3.3 | Parents and teachers have low expectations regarding the academic achievement of a child with CHD

Parents of a child with CHD fear for the future, especially when they know that he or she will have to undergo further surgery.

> I do not know what lies ahead for my son, I prefer not to think about it. But as they've told us that he needs another operation, you can't avoid thinking about it, and it's really hard (Parent 4).

> There are times when I don't want to think about the future. I'm aware that my son won't make it to 60. Who knows what the future holds… in the long term (Parent 3).

As for teachers, they tended to expect only the minimum academic results from these children, and notably the children themselves felt they were treated differently to their healthy peers.

> We do not push them if we know they find it hard (Teacher 2).

Sometimes they don't ask me to do what the others are doing (Child 5).

Sometimes my classmates do it first, and then it's my turn, so I don't get tired and all that (Child 4).

I need a bit more support than the other children (Child 1).

The reasons given by teachers, for demanding and expecting less of these children had to do with a fear of provoking a negative physical reaction and the wish to avoid undermining their self-esteem by setting them tasks they were unable to do. The risk, however, is that the possible potential of a child with CHD may, therefore, go unrecognized. This is an important issue because research suggests that with adequate support, these children can, by the time they reach adolescence, achieve academically on a par with (Schaefer et al., 2015) or even better than many of their healthy peers (Pfitzer et al., 2019).

What we start out doing is modifying or adapting the activities a little, because we're afraid that they'll overdo it at school and that something might happen to them (Parent 6).

Trying to keep up isn't good for their self-esteem. So, we adapt what we do in math and language classes (Parent 6).

She works in silence and you do not notice her, but she stands out in her work (Parent 11).

Teachers also saw the child with CHD as someone who behaved differently to "normal" children and who required more individualized input. A "normal" child was described as one who was happy sitting down and working, and intelligence was equated with being quicker than others at doing things.

He'll push the paper aside and sometimes he doesn't know what he has to do. Before you know it he's over looking at the toys. He needs individual attention, always, to carry on working, to stay focused on something for a while (Teacher 2).

We believe that where they can achieve the most is in ordinary school, alongside normal children, normal patterns of behavior … There with the rest of the class, sitting normally, enjoying whatever task they're doing (Teacher 2).

Some children are more intelligent and are quicker than others in everything (Teacher 6).

Many of the teachers said that children with CHD often struggle to concentrate (Kallfelz et al., 1992), and this can add to the difficulties that some of them have with understanding and remembering the content of lessons. Farr et al. (2018) similarly found that parents of children and adolescents with CHD commonly reported that their child had difficulties with learning, concentration, and communication.

This girl has difficulties understanding everything, and also with her memory (Teacher 5).

They usually find it hard to concentrate, and this means they're a bit behind. They often can't remember things. They'll learn something today, and tomorrow you'll have to repeat it (Teacher 6).

Pfitzer et al. (2019) noted that these children were more likely to present behavior and psychomotor disorders, increasing the probability of having to repeat a school year. A common experience for all these children is fatigue.

Consequently, they tend to move around less, thus hampering their personal development through reduced opportunities to explore their surroundings. For teachers, the fact that these children require more individualized attention is also related to their increased dependency and need for constant approval.

> She's a really placid little girl. They're really not very active (Teacher 6).

> They get tired easily, so few opportunities to explore, to move around, and this diminishes them (Teacher 3).

> She's very dependent. She likes you to look over her drawings, "look at mine". She always wants you to congratulate her, to draw attention to her (Teacher 2).

In summary, professional seem to expect minimal academic results. At the same time, this makes children report that teachers treat them differently from their peers while parents believe that teachers demand less of their children and avoid areas that will be challenging for children to avoid lowering children's self-esteem and fear. Moreover, they believe children with CHD require more individualized care, which they report is related to their dependency and need for constant approval. Parents fear for the future of their children, particularly when they have to undergo surgery.

3.4 | Children with CHD experience exclusion from peer group social learning activities

Children with CHD feel disillusioned because they are unable to do what others do. Fatigue is a common feature of their condition, and it places considerable limits on their ability to join in with games and activities (Birks et al., 2007). This is a particular issue for boys, who tend outside of school to engage in more competitive games that involve physical activity (Birks et al., 2007).

> I feel really bad when I can't do what the others are doing. I tell them I'm not playing anymore, that it's better for me (Child 3).

> I feel really down when I see that I can't do what the others are doing (Child 5).

> When I get tired and I can't do a lot of things, I feel really left out (Child 1).

> I can't play football. I can do other things as long as I don't have to run. The others don't help me, because they just want to play (Child 3).

For these children, their friends are those who are happy to play games or do things that they (the child with CHD) can also do. However, these are more sedentary activities, and consequently they may be viewed less favorably by parents of healthy peers.

> My friends include me in whatever, but the other kids do not (Child 2).

> I go to the cinema with my friends (Child 1).

> My friends from school do not invite me to do things together at the weekend (Child 5).

What I most like doing is sleeping and playing on the computer (Child 1).

I play Goku [a video game] with my cousin, Adrian, that sort of thing (Child 3).

My friends come to my place and we play video games (Child 5).

As a result of their condition, these children experience both hopeless and disillusioned: Hopeless in the face of a life they haven't chosen and which is different to that of others, and gratitude for the mere fact of being alive despite the problems they were born with.

I wish I could change the way I feel, because I'm often really sad (Child 1).

He was saying really odd things, like he wanted to die and that he did not want to go on living (Parent 4).

He knows what he's got, but he does not accept it. He'll say, why me, and why not, for example, his brother, why is he the one who cannot do things. He does not accept it. But eventually you find a way of explaining to him that lots of people have problems of one sort or another, and this is the one he has to deal with (Parent 3).

He felt… it affected him… and he'd say to me… about him having this wrong with his heart and needing an operation, whereas his brother did not (Parent 6).

He asks himself why me, what have I done to deserve this (Parent 4).

I'm grateful to be alive. Yes, because I think that having this disease and then not dying means that I'm really lucky to be alive (Child 1).

If I had three wishes, I'd ask to be a multimillionaire and immortal (Child 5).

When a person's perceived self-image differs greatly from the ideal, there is a strong likelihood that the associated anxiety will be such that it leads to the development of a negative self-concept and a depressive mood state (González-Pienda et al., 1997).

In general, the teachers we interviewed agreed that children tend to be intolerant of others who are different in some way, such as a classmate with CHD. Studies show that children with chronic physical illness or disability are more likely to be bullied (Faith et al., 2015; Pinquart, 2017), especially when they perceive a lack of support from parents (Beran, 2008). This has to do with the impact of their illness and treatment on physical appearance (Pinquart, 2017), as well as their need to abstain from normative activities engaged in by peers (Faith et al., 2015). For teachers, however, having a child with CHD in their classroom is an opportunity to address the issue of tolerance as part of all the children's personal development.

Or sometimes with Alexia, because of her color. There's a problem of intolerance, which we're working on (Teacher 2).

You try to ensure that all the children are treated the same. That there's respect and tolerance, appreciation of each other. You encourage this and work on it (Teacher 3).

> Having children with problems is a way of showing the others how to care for another person, through what we do when they come back still convalescent, or when they have to go for treatment. It's all a chance to learn (Teacher 2).

In summary, professionals reported that children tend to be judgmental with peers that are different. However, having a peer with CHD is an opportunity to work on tolerance as part of the personal development of the class group. Children report feelings of disappointment because they cannot do what their peers do. They play with friends, but activities are exclusively sedentary. Furthermore, they report feelings of hopelessness because they feel different from everyone else, and gratitude for being alive. Interestingly, parents think that their children do not accept their illness and sometimes show suicidal ideation.

4 | DISCUSSION

The results of this study indicate that the children in our sample are not currently afforded the same social learning opportunities as their healthy peers. Consequently, their experience of schooling falls short of being inclusive. Overall, our analysis suggests that our caregiver cohort struggles to encourage their child with CHD to achieve academically and engage socially, that children themselves often have poor self-esteem due to the low expectations placed on them by parents and teachers, and teachers in our sample feel they receive insufficient support and advice from the education and health care systems.

In relation to the noninclusive education of these children the family environment plays a key role when it comes to helping children cope with chronic illness and live as normal a life as possible (Muscara et al., 2017). In relation to schooling children, some parents find it difficult to offer the supportive encouragement and positive reinforcement the child needs (Seki et al., 2017). Importantly, parents who are overprotective as a result of their child's condition may unwittingly leave him or her more vulnerable to bullying (Sewarer, 2011). The overprotective attitude of parents may come from a worry about their children's health. According to an adaptation of Maslow's hierarchy of needs for parenting goals has shown that parents' main concern is their children's survival. Once this need has been met, they can move on to the next level of needs, including quality of life (Kenrick et al., 2010). The quality of life of people with chronic conditions is also influenced by attitudes toward illness, and as Azzollini and Bail (2010) point out, positive attitudes can help the affected individual to experience illness as a challenge rather than as a threat. In this context, another study found that loneliness and depressive symptoms among adolescents with CHD were related to the parental support received, highlighting the potential need for simultaneous psychosocial interventions targeting both the adolescent and the parents (Luyckx et al., 2014). Bright et al. (2013) argue that this is especially important in the case of parents who perceive their child with CHD as being fragile and vulnerable, as was the case with some of our participants.

Although learning of their child's CHD diagnosis is traumatic for parents, experiences of this kind do not necessarily lead to negative psychological outcomes (Hornor, 2017). Indeed, research by Wray et al. (2001) suggests that these families may become closer and more cohesive, and better able to manage conflict as a result of their experience. The ability to achieve healthy adjustment even in the face of adversity is commonly referred to as resilience (Connor & Davidson, 2003). Resilient individuals tend to have a flexible approach to life's challenges, and they cope by making use of a range of protective resources, including individual attributes, family support and cohesion, and external support systems (Hornor, 2017). This highlights the importance of supporting the parents of a child with CHD so that they are able to adequately meet his or her psychosocial needs (Wiseman et al., 2018), although intervention should focus more on how they perceive and cope with the child's illness rather than its actual severity (Hill & Morrison, 2020). Because promoting more positive parenting behaviors may also improve the child's social adjustment, it can also help to reduce the risk of the child being bullied at school (Faith et al., 2015). Overall, this suggests that the therapeutic care of children with CHD or other complex conditions could usefully

include interventions aimed at helping parents to become more resilient. This therapeutic care would also aid social learning in schools, and thus support the child's development.

Self-esteem is a determining factor in students' academic and social achievement (Trautwein et al., 2006), and recent research suggests that the well-being of adolescents with chronic illness can be enhanced by improving their self-esteem and peer relationships (Lee et al., 2019). As Goleman (1999) points out, cognitive ability alone is no guarantee of academic, professional, and personal success. Indeed, students need confidence in their own abilities and a strong sense of self-efficacy to engage with learning tasks and objectives, and by doing so they may benefit both academically and emotionally (Vega & Garcia, 2009). A study by Ruggiero et al. (2018) involving parents of children with CHD of different ages found that older children were perceived by their parents as having more difficulties at school, especially as regards problem-solving when something bothered them, solving math problems, and writing school papers. However, research carried out in Germany by Pfitzer et al. (2019) found that many young people with CHD achieved better grades than many of their peers by the end of high school. In this context, it is worth noting that according to the most recent Program for International Students Assessment (PISA) report, the educational achievement of students in our country, Spain, was below the European average, whereas German students were among the highest achievers (Organisation for Economic Co-operation and Development [OECD, 2018). This may indicate cross-national differences in the quality of education systems, which might also imply differences in the amount of resources invested in ensuring inclusive education in the group of children with CHD in particular and children with CSC in general.

As Anderson-Butcher and Ashton (2004) point out, this underlines the importance of collaboration between schools and other agencies (including health care and community services) to ensure the educational success of these children. Interprofessional collaboration between teachers and health care specialists is especially important in the case of children with CHD (Glover et al., 2015). It is noteworthy, therefore, that many of the teachers we interviewed felt they received insufficient support and advice regarding the care needs of children with CHD, making inclusive education more difficult to achieve in practice. This lack of support and the challenges it poses for children's inclusion was highlighted in a study conducted in Japan by Seki et al. (2017) who concluded that in the absence of adequate resources it may be better for chronically ill children to attend classes that are adapted to their special educational needs. This is especially relevant in the case of children in whom both ventricles are affected, as this implies more surgery or catheter interventions and, therefore, increased absence from school (Gerstle et al., 2016; Pfitzer et al., 2019). Buratti et al. (2016) found that parents' ratings of the cognitive difficulties experienced by their child with CHD were closely correlated with the child's performance on objective measures of intellectual functioning.

The transition back to school after prolonged absence due to illness is easier when there is continuous learning support and when relationships with the teacher and classmates are maintained during the absence (Hen, 2022). Parents' emphasis is placed on school and social activities, believing that their child with CHD has fewer opportunities than their peers. On the other hand, professionals place emphasis on minimizing any potential academic delay. There is a disconnect between parents and professionals, where parents report that professional lack interest and professionals believe that parents mistrust them. Children report feeling different from their peers while also being treated differently, which makes them feel hopeless and disillusioned.

Giroux et al. (2019) noted several barriers to effective collaboration and communication between health professionals and educators, including a lack of financial reimbursement for nonschool personnel, differing expectations among health and education professionals, clinicians' lack of knowledge about educational processes, and a lack of understanding among teachers of clinical and treatment procedures. Importantly, collaboration between different agencies also requires good coordination so as to avoid duplication or gaps in service provision that both undermine the quality of what is offered and increase overall costs (Fuchs, 2009). However, programs or organizational structures that enable this level of coordination across different children's services are generally lacking, with a major barrier being limited funding and mechanisms for reimbursing providers (Petitgout et al., 2012).

Taken together, these findings suggest that an interesting topic for future research would be to explore whether cross-national differences in interprofessional collaboration and coordination are reflected in differences in variables such as family resilience and the self-esteem and academic achievement of children and adolescents with complex health needs.

Finally, our findings support the importance of interprofessional collaboration. Various studies have previously found that the presence of a school nurse can reduce illness-related absence from school and improve the management of children with more complex health needs (Engelke et al., 2014; Moricca et al., 2012; Pennington & Delaney, 2008). Additionally, parent-perceived health-related quality of life in children with chronic illness might have a direct effect on health-related behaviors such as school attendance (Emerson et al., 2016).

Tabata (2017) reports that having a nurse on staff can help schools to meet the health needs of all enrolled children, including those with chronic illnesses such as CHD. Boyle et al. (2015) similarly argue that the school nurse has a key role to play in designing and coordinating individualized care plans that address, from a multidisciplinary perspective, the physical, psychosocial, and educational needs of children with CHD across different developmental stages. These findings support the growing area of hospital pedagogy, a field based on the interdisciplinary collaboration of health and educational professionals to meet the needs of patients as an integrative action that ensures the rights of individuals in situation of illness and convalescence with the aim of improving personal, familial, and social well-being (Violant, 2017). Taken together, these findings suggest that an interesting topic for future research would be to explore whether cross-national differences in interprofessional collaboration and coordination are reflected in differences in variables such as family resilience and the self-esteem and academic achievement of children and adolescents with complex health needs. Additionally, future research should conduct international comparison studies in countries with alternative services for children with chronic illnesses, such as The Individuals with Disabilities Education Act (IDEA) in the United States.

4.1 | Limitations

The present study has two main limitations that need to be considered. The first is that the data were obtained from key stakeholders within the specific context of the Spanish education system, and it is, therefore, unclear to what extent the findings might be generalizable to other sociocultural settings. Further comparative studies are required to explore whether the challenges we identified with respect to inclusive education and children with CHD are present within the education systems of other countries. A second potential limitation is that all members of the research team were women, as this may, given the close association between female gender and motherhood, have influenced their interpretation of the interview data. To address this potential bias, we carried out an extensive literature review to compare our interpretation with previous findings and provide support for the theoretical narrative that is presented in the results section of this paper.

5 | CONCLUSION

The experiences and perceptions of the current sample would suggest reduced social learning opportunities for children with CHD or other complex care needs within the Spanish education system. Their experience of schooling thus falls short of being inclusive. Through interviews with key stakeholders (children, parents, and education professionals), we identified several contributing factors and challenges in this respect. One is that some parents see their child with CHD as a fragile individual and school as a hostile environment in which the child's limitations and needs are not adequately recognized. This can lead them to be overprotective, and they may find it difficult to offer the supportive encouragement and positive reinforcement the child needs. Another prominent issue in the interviews are the low expectations placed on them by both parents and teachers with regard to their academic and

personal development something that can contribute negatively to the vision they have of themselves. Notably, many of the teachers we interviewed felt that in the absence of adequate support from the education and health care systems, the best they could do was to make minor adjustments to what and how they taught in an attempt to include these children beyond curricular adaptations.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

The study was approved by the Institutional Review Board of Rovira i Virgili University (Spain). All the children gave informed assent and all adult participants (parents and education professionals) signed informed consent. A data protection protocol was established in accordance with current legislation in our country.

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