

# Exploring Health-related Problems After Pediatric Congenital Heart Surgery: A Qualitative Study

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## Research Article

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# Abstract

**Background:** It is essential to assess the quality of life after discharge of children who have had congenital heart disease (CHD) surgery. However, the factors affecting the early quality of life of children after the operation are complex. To identify health-related problems of patients after CHD surgery from October to December 2020 by interviewing their health care providers and encoding these using the International Classification of Functioning, Disability, and Health for Children and Youth Vision (ICF-CY) to identify the elements affecting health, as well as to assist health care providers in evaluations and interventions during follow-up.

**Methods:** Fourteen multi-center doctors, nurses, and rehabilitation specialists and 18 parents were interviewed, and the ICF-CY classification system was used for encoding and analysis.

**Results:** Forty-nine unique ICF-CY codes were obtained, including 31 (63.27%) codes of body functions, 4 (8.16%) codes of body structure, 7 (14.29%) codes of activity and participation, and 7 (14.29%) codes of environmental factors.

**Conclusion:** ICF-CY provides a comprehensive method to record the health problems of children after CHD surgery. Based on the findings of this study, we can further develop assessment tools for cardiac rehabilitation, encompassing the heart, immunity, respiration, digestion, metabolism and endocrine system, psychology, and family, and conduct comprehensive management via a multidisciplinary team.

## Introduction

Currently, the postoperative mortality of congenital heart disease (CHD) in some professional pediatric heart centers has decreased to 2%-3% [1] due to the following: improvement in surgical skills, cardiopulmonary bypass technology for myocardial protection, advanced postoperative monitoring, and the application of extracorporeal membrane oxygenation. Our previous study [2] found that postoperative mortality was lower and the disease severity was significantly higher in 2016–2019 than in 2012-2015. It is thus essential to assess the quality of life after discharge of these surviving children after critical congenital heart surgery.

Early studies have shown that the total score and each dimension score of these children's quality of life within one year after surgery were significantly lower than those of children more than one year after surgery [3]. There are many factors that affect the low level of the early quality of life, including personal factors, such as the complexity of the disease [4], postoperative medical treatment [5], and cyanosis [6]. Parents are also important factors, including their psychological state [7], knowledge [8], and coping style [9]. The socio-economic status of the family is another factor, which may lead to all-cause mortality and unplanned readmission rate [10]. The factors affecting the early quality of life of postoperative children are complex and need to fully understand the problems of children from health care providers (including professional medical staff and parents) in the period of cardiac rehabilitation, to carry out targeted research.

The International Classification of Functioning, Disability, and Health (ICF) is an international classification system developed by the World Health Organization that focuses on health and functioning rather than medical diagnosis. The ICF version for Children and Youth (ICF-CY), published in 2007, has the same structure [11]. At present, ICF-CY has been used to evaluate the health status of children with diseases to improve quality of life and can also be applied to the conceptual model of clinical intervention and adaptive training services [12]. The introduction of the ICF-CY classification system can help sort out clinical problems and determine the degree of children's health after CHD surgery.

The purpose of this study was to record the health-related problems after pediatric CHD surgery through interviews with health care providers (including professional medical staff and parents), and to sort out the common problems existing in body function, body structure, activity and participation, and environmental factors by means of ICF-CY classification system.

## Methods

### Design

This study used qualitative methodology, which reflects a phenomenon by describing the individual's experience in the real world [13]. In this study, all the subjects involved in health care in the process of cardiac rehabilitation within one year after CHD surgery were interviewed, encoded and analyzed using ICF-CY classification system [11], to comprehensively reflect the problems of children in this critical period. This study was granted ethical approval by Shanghai Children's Medical Center, an affiliate of Shanghai Jiaotong University School of Medicine (SCMCIRB-K2021002).

### Participants

This study was conducted from the perspective of medical staff and patients to explore the problems after congenital heart disease surgery. The studied groups were interviewed separately. The 14 medical staff for the interview came from the top children's congenital heart disease diagnosis and treatment centers in four cities in China, including Fuwai Hospital of Chinese Academy of Medical Sciences, Shanghai Children's Medical Center, Guangzhou Women's and Children's Hospital, and Kaohsiung Veterans General Hospital. There were three paediatric cardiac follow-up specialist nurses, two rehabilitation therapists, five cardiac physicians, and four cardiac surgeons. A total of 18 parents participated in this study, all of whom underwent CHD surgery in the first year (see Table 1). The investigation conforms to the principles outlined in the Declaration of Helsinki. All interviewees signed an informed consent.

### Data collection

From October to December 2020, a total of 32 parents and medical staff were interviewed semi-structurally, with an average interview time of 45 min. The interview framework was derived from the ICF-

CY classification and included domains of body structure and function, activity and participation, and environment.

The interview outline for the medical staff included the following questions: During the postoperative follow-up, which parts of the child's body are prone to problems? Which aspects are prone to change in the child's attitude, participation in activities, education, and social participation, that are not as good as before/different from their peers? Do parents express that the difficulty in the daily care (daily life and disease management) of the child has increased?

The outline of the interview for the child and their family included the following questions: After the CHD operation, which parts of the child do you think have problems? What do you think has changed in the child's spirit, participation in activities, school, and social activities, and what are the differences between the child and their peers? Do you think the daily care (daily life, disease management) of the child is more difficult than before the operation? What problems do you think the child still has after surgery? How are you trying to solve those problems? What do you think is helpful for you and your child's living environment?

## **Data analysis**

The process of encoding transcribed interview materials into the ICF-CY followed several steps, modeled on Cieza's rules [14]. Step 1: The transcribed interviews from all participants were read, until all the information was confirmed to be saturated. Step 2: Content analysis [15] was performed and texts with meaningful concepts were identified. Step 3: Meaning units revealed information about the child's body structure, function, activity, participation or environment were extracted. Step 4: One or more tags describing the content of the meaning units were identified from meaning units and linked to an ICF-CY code as accurately as possible. Meaningful units that cannot be linked to ICF-CY were assigned to categories of indeterminate content [11].

## **Validity**

An inter-rater reliability test was performed by two of the authors by separately encoding its associated ICF-CY codes, and the third author was responsible for determining the differences. The consistency of ICF-CY from two authors was good ( $\kappa = 0.831$ ).

# **Results**

## **The outcomes of ICF-CY codes**

Finally, 345 concepts were extracted from the interview content, and 183 independent concepts remained after duplication, of which 171 concepts could be linked to 52 ICF-CY categories (the effective link rate was 93.4%). After the removal of the repetitive parts, there were 49 unique secondary ICF-CY codes, including 31 (63.27%) for the body function, 4 (8.16%) for the body structure, 7 (14.29%) for the activity and participation, and 7 (14.29%) belonging to the environmental factors (Table 2).

## Features of health-related problems

In this study, several ICF-CY codes focused on the common themes of medical staff and parents. Overlap and difference between groups were represented through a Venn diagram of the features of health-related problems (Figure 1).

### Commonality

*Functions of the cardiovascular, haematological and respiratory systems.* It is found that there were still some problems in cardiopulmonary, haematological and respiratory systems function after CHD surgery, especially if there were residual problems in anatomy, fatigue after exercise was common:

Sometimes my kid walk, run...maybe... about half an hour... his lips became a little bit dark and he felt tired and wanted to held in my arms. (Parent 17)

If he has residual problems, such as pulmonary regurgitation or tricuspid regurgitation, he always feel fatigue. (Medical staff 1)

*Functions of digestive, metabolic and endocrine system.* Medical staff and parents have said that children may be obese or emaciated after CHD surgery, which was mainly related to children's eating behavior, stomach intake and absorption.

She eat less than a normal child. She can't chew well. She chews very slowly and always wants to have a break. (Parent 10)

Usually, some are in the poor after the operation...the appetite are not good... (Medical staff 4)

*Mental functions.* The neurocognitive psychology of children with congenital heart disease after operation was lower than that of their normal peers.

The intelligence of my kid is worse than that of children of the same age. At least children of the same age can express themselves clearly. And they can at least calm her down. My kid can't, she can't... I brought her to the rehabilitation center...The doctor said that her intelligence might be one and a half years slower than her peers. (Parent 10)

*Voice and speech functions.* After the CHD operation, the ventilator may cause the children's voice disorder in a period of time after the operation.

During the follow-up, a little girl who had a CHD operation in our hospital talked to me with an weird voice. She can't make a normal sound. Then I asked her father when this voice happened like this. He said, yes, that was it after the operation, but it didn't affect her daughter drinking water and eating. (Medical staff 5)

At the beginning, when she (her daughter) just finished the operation, her voice was small... A few months later, she still couldn't speak out in her voice . (Parent 4)

Parents play a very important role in the cardiac rehabilitation stage, including *stress management and disease management ability of parents*. The lack of disease knowledge led to parents excessive pressure and worries that self-management affect the later rehabilitation of children.

We are worried about his recovery. Dr Zhu said that his operation was very successful, but it can't guarantee the recovery in the later stage. We are really under great pressure. We are afraid that because of some of our mistakes, some things we don't pay attention to may lead to his worse conditions. (Parent 16)

Parents are afraid to have PE classes. children after cardiac surgery always leave alone in the classroom. I always tell the parents normal activities should not be avoided. (Medical staff 2)

*Health services, systems and policies*. The backward medical level, especially in remote areas, can not meet the needs of postoperative rehabilitation of CHD.

In fact, when these children go back to the local area, there is lack of professional institutions to continue their rehabilitation. The local medical institutions are generally backward and the medical staff are lack of experience to treat with pediatric cardiac patients.It's better for these children to go to a higher level hospital. (Medical staff 5)

### **Differences in the medical staff**

*Wound recovery and infection*. Most surgeons would pay attention to the prognosis of the wound after surgery.

In the early period of rehabilitation, I will also focus on the assessment of the incision, including whether there is infection or the poor healing of the incision. (Medical staff 4)

*Self care*. For children undergoing rehabilitation training, the rehabilitation therapist would focus on teaching children the skills of disease self-management and self-monitoring.

When the older child is in the second phase of rehabilitation, he has no ability to calculate his heart rate. I will tell him what it's like in exercise training and how to teach him to self-monitor in daily life. (Medical staff 13)

### **Differences in the parents**

*Movements related issues*. Limb discordance can occur after some complex CHD surgery, resulting in the need for additional physical therapy.

After Glenn shunt surgery, her left limb movement was uncoordinated due to the hypoxemia during ICU. Now the recovery is very slow. (Parent 16)

*Environment problems.* Parents in remote areas would also be worried about the recovery of their children due to the altitude.

Because Inner Mongolia is very cold, it is said that it belongs to the plateau, so it is not very good for her circulation. (Parent 12)

## Discussion

Based on the ICF-CY, we identified 49 codes for paediatric patients in the first year after CHD surgery. Using ICF-CY category docking, we found that the recovery of CHD can involve a variety of functions. Among these, the cardiopulmonary function after the CHD operation requires more attention. The existing problems include arrhythmia, hypoxia, or cyanosis after activity, and frequent respiratory diseases, which are related to prognosis. Therefore, a growing number of heart centers have introduced a cardiopulmonary exercise test to evaluate the patient's cardiopulmonary function during postoperative rehabilitation, as well as to propose relevant postoperative exercise programs based on the reported results [16].

Besides, both medical staffs and parents indicated that the children's food intake was low, their weight was lower than normal, and growth and development was slow. Malnutrition in CHD is a global problem. In the early rehabilitation stage after the operation, the proportion of malnutrition in children was significantly higher than that before operation, and the reason was related to the treatment in the ICU and the operation [17]. Chronic malnutrition after the operation was mainly related to the residual heart shunt, higher Ross score, and long-term oral diuretics [18]. Paying attention to the trend in the nutritional indicators within one year is a prediction of the trend of the cardiac function and quality of life in children.

We also found that some children experience strong reactions and emotional experiences, i.e., emotional fluctuations, anxiety, and an inferiority complex. Children with CHD had higher risks for poor behavior, emotional management, and cognition because of ischemia and hypoxia or gene deletion [19]. Previous cohort studies showed that children with CHD (regardless of type) were twice as likely to suffer from mental illness compared to healthy children, especially with internalized behavior problems, social interaction problems, decreased quality of life, developmental retardation, and academic difficulties [19, 20]. In recent years, studies have confirmed that cyanotic CHD before operation due to arterial hypoxemia, cerebral perfusion damage, or both leads to poor oxygen delivery, and intraoperative, cardiopulmonary bypass technology may be associated with hypoxic-ischemic reperfusion brain injury, and postoperative medical complications may increase the risk for brain injury[21]. Meanwhile, the scar, decreased activities, and social restrictions after the operation aggravate the inferiority complex of children. Therefore, it is very important to evaluate the mental functions early and provide guidance and intervention according to children's personality characteristics.

Meanwhile, the attitude of health care providers (including parents and medical staff ) to children is very vital. Previous studies indicated that the parents of children after CHD surgery have serious psychological problems (anxiety and depression) and a low coping ability leading to low family management function [22]. In this interview, parents were often directly judge the recovery level of the child's disease by improving activities and growth with their peers. These "self-empirical" management methods are prone to misjudgment and delay disease treatment when taking care of critically ill children. In addition, the children in this study generally live in provinces, cities, and rural areas thousands of kilometers away from the follow-up hospital. Due to the imbalance of medical resources in China, local health services are limited in paediatric medicines, cardiac ultrasound level, and children's health care services. The hardware for postoperative follow-up and monitoring of these children is also one of the difficulties that needs to be resolved in the future.

In addition to the above common codes, the study found that there were differences in ICF-CY codes of postoperative health problems between medical staff and parents. Medical staff pay attention to wound healing and improve the skills of older children to learn self-care skills. Parents' concerns are more scattered and detailed, including the children's postoperative movement problems and the impact of living environment. These codes from medical staff and parents respectively show that the health of children after CHD surgery will be affected by multi-dimensional complex factors, so it is necessary to comprehensively evaluate children from multiple perspectives.

## **Limitations And Strengths Of This Work**

The patients in this study were all from one paediatric heart center and this may have caused a certain degree of bias. However, these patients came from different provinces and cities throughout China and underwent various types of CHD surgery. The expert interviews from four regions could have made up for the bias to a certain extent.

## **Conclusion And Clinical Implications**

Cardiac rehabilitation within one year after CHD surgery is very important, but there is a lack of guidance on the content and mode of paediatric cardiac rehabilitation after CHD surgery, which leads to great differences among various centers. This study found that the content of cardiac rehabilitation within one year after CHD surgery should not be limited to the recovery of cardiac structure and function. We can further develop assessment tools for the cardiac rehabilitation stage, covering the heart, immune system, respiration, digestion, psychology, and family with a multidisciplinary team that conducts comprehensive management. Through the effective interaction between health care providers, the cardiac rehabilitation and quality of life within one year after CHD surgery can be better improved.

## **Abbreviations**



ICF-CY: International Classification of Functioning, Disability and Health for Children and Youth; CHD: congenital heart disease

## **Declarations**

### **Ethics approval and consent to participate**

This study was granted ethical approval by Shanghai Children's Medical Center, an affiliate of Shanghai Jiaotong University School of Medicine (SCMCIRB-K2021002). The investigation conforms to the principles outlined in the Declaration of Helsinki. All the parents and children was voluntary and had the right to withdraw at any time without prejudice. The Written informed consent was obtained from the parents for their children after CHD surgery.

### **Consent for publication**

Not applicable.

### **Availability of data and materials**

The data supporting the findings are contained within the manuscript and additional files. The anonymized datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

### **Competing interests**

The authors declare that they have no competing interests.

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### **Authors' contributions**

Wen-Yi Luo participated in the study design, collection and analysis of the data and the writing of the report. Ping Ni participated in the study design, analysis and interpretation of the data. Xin-Yue Liu and Lin Chen participated in data collection, analysis and the interpretation of the data. Yong-Mei Guan, Hao Zhang and Ya-Qing Zhang participated in the interpretation of the data, and all authors revised this article critically, approved the final manuscript and agreed to its being submitted for publication.

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## Tables

**Table 1 The characteristics of the patients included in this study**

No	Diagnosis	Operation	Month after operation	Parent	Region
1	SAS	Radical operation	3 m	Mother	Zhe Jiang Province, East China
2	PA/IVS	B-T shunt	2 m	Father	Jiang Xi Province, East China
3	TA	Fontan	2 m	Mother	An Hui Province, East China
4	PA+VSD	Radical operation	12 m	Mother	Jiang Su Province, East China
5	SAS	Radical operation	3 m	Father	Gui Zhou Province, West China
6	MR	Mitral valvuloplasty	6 m	Mother	Gui Zhou Province, West China
7	VSD	Radical operation	12 m	Mother	Jiang Xi Province, East China
8	PS+VSD	Radical operation	5 m	Father	Yun Nan Province, West China
9	TOF	Radical operation	7 m	Father	An Hui Province, East China
10	PA/IVS	Glenn	12 m	Father	Shan Dong Province, North China
11	TOF	Radical operation	6 m	Mother	An Hui Province, East China
12	PS	Radical operation	5 m	Mother	Inner Mongolia Autonomous region, North China
13	COA	Radical operation	6 m	Father	An Hui Province, East China
14	PA+VSD	Extended pulmonary angioplasty	5 m	Mother	An Hui Province, East China
15	SAS	Radical operation	4 m	Mother	Jiang Xi Province, East China
16	PS	Extended pulmonary angioplasty	4 m	Father	Jiang Xi Province, East China
17	AS	Ross	5 m	Father	Hu Bei Province, Central China
18	CAVC	Radical operation	9 m	Mother	Jiang Su Province, East China

SAS, supraaortic stenosis; PA, pulmonary atresia; TA, tricuspid atresia; MR, mitral regurgitation; VSD, ventricular septal defect; PS, pulmonary stenosis; TOF, Tetralogy of Fallot; COA, coarctation of aorta; AS, aortic stenosis; CAVC, complete atrioventricular canal

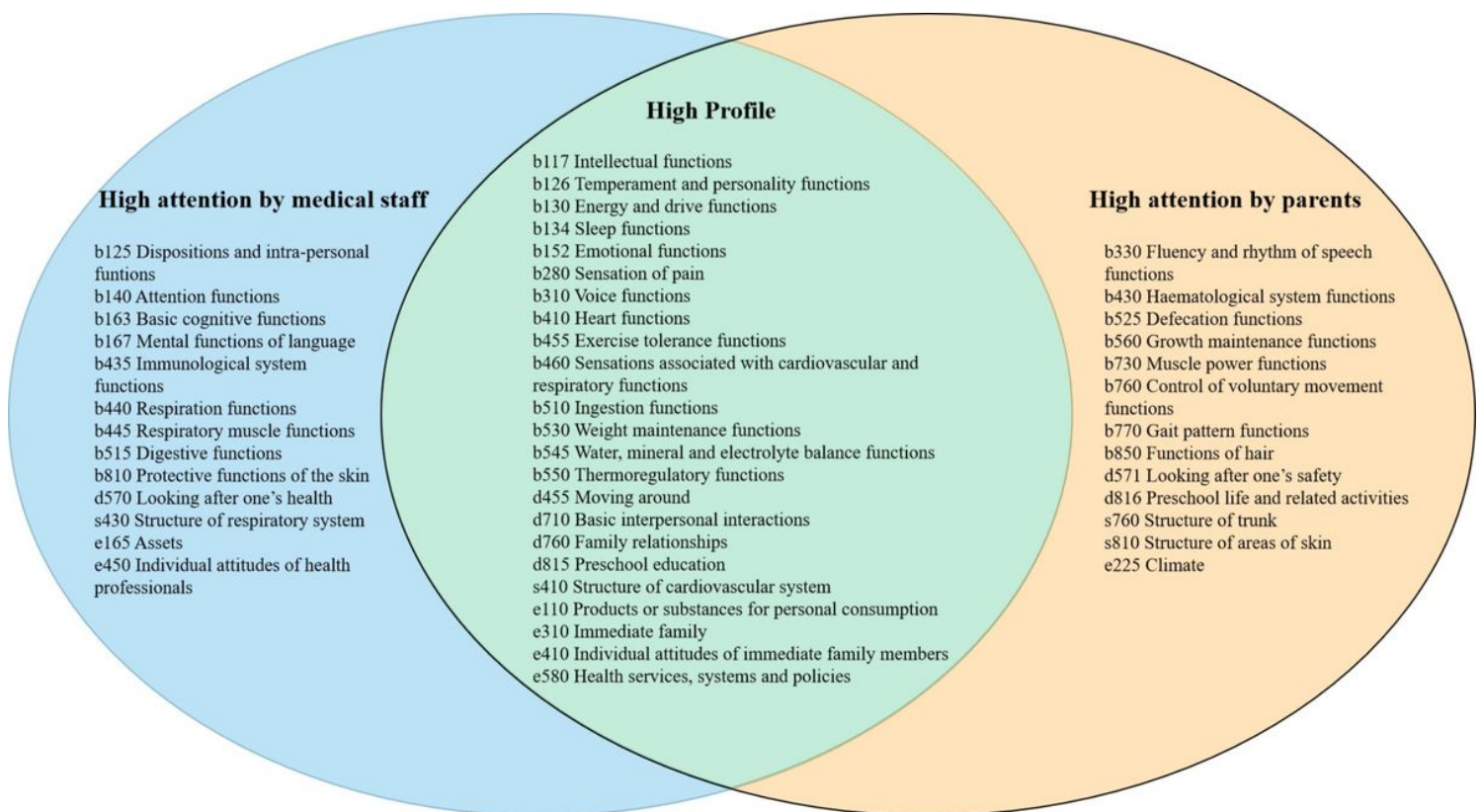
## Table 2 General distribution of ICF-CY codes

Component	domain	Codes n (%) (N=49)	Codes
Body functions	b1 Mental functions	9(18.4)	b117 Intellectual functions
			b125 Dispositions and intra-personal functions
			b126 Temperament and personality functions
			b130 Energy and drive functions
			b134 Sleep functions
			b140 Attention functions
			b152 Emotional functions
			b163 Basic cognitive functions
			b167 Mental functions of language
			b2 Sensory functions and pain
b3 Voice and speech functions	2(4.1)	b310 Voice functions	
		b330 Fluency and rhythm of speech functions	
b4 Functions of the cardiovascular, haematological, immunological and respiratory systems	7(14.3)	b410 Heart functions	
		b430 Haematological system functions	
		b435 Immunological system functions	
		b440 Respiration functions	
		b445 Respiratory muscle functions	
		b455 Exercise tolerance functions	
b5 Functions of the digestive, metabolic and endocrine systems	7(14.3)	b510 Ingestion functions	
		b515 Digestive functions	

			b525 Defecation functions
			b530 Weight maintenance functions
			b545 Water, mineral and electrolyte balance functions
			b550 Thermoregulatory functions
			b560 Growth maintenance functions
	b7 Neuromusculoskeletal and movement-related functions	3(6.1)	b730 Muscle power functions
			b760 Control of voluntary movement functions
			b770 Gait pattern functions
	b8 Functions of the skin and related structures	2(4.1)	b810 Protective functions of the skin
			b850 Functions of hair
Activity and participation	d4 Mobility	1(2.0)	d455 Moving around
	d5 Self-care	2(4.1)	d570 Looking after one's health
			d571 Looking after one's safety
	d7 Interpersonal interactions and relationships	2(4.1)	d710 Basic interpersonal interactions
			d760 Family relationships
	d8 Major life areas	2(4.1)	d815 Preschool education
			d816 Preschool life and related activities
Body structures	s4 Structures of the cardiovascular, immunological and respiratory systems	2(4.1)	s410 Structure of cardiovascular system
			s430 Structure of respiratory system
	s7 Structures related to movement	1(2.0)	s760 Structure of trunk
	s8 Skin and related structures	1(2.0)	s810 Structure of areas of skin
Environmental factors	e1 Products and technology	2(4.1)	e110 Products or substances for personal consumption

		e165 Assets
e2 Natural environment and human-made changes to environment	1(2.0)	e225 Climate
e3 Support and relationships	1(2.0)	e310 Immediate family
e4 Attitudes	2(4.1)	e410 Individual attitudes of immediate family members
		e450 Individual attitudes of health professionals
e5 Services, systems and policies	1(2.0)	e580 Health services, systems and policies

## Figures



**Figure 1**

Venn diagram of the features of health-related problems mentioned by health care providers