ABSTRACT
Aims To describe the ways in which parents recognise and make decisions about their child’s symptoms following discharge home after congenital heart interventions in the first year of life and their experiences of seeking help.
Methods This was a qualitative study involving semistructured interviews with parents. Twenty-one parents were recruited to the study. Parents all had a child who had congenital heart surgery in their first year of life between September 2009 and October 2013 at one of three UK cardiac centres; the children had either died or were readmitted as an emergency following initial discharge.
Results Some parents were unable to identify any early warning signs. Others described symptoms of deterioration including changes in feeding and appearance, respiratory distress and subtle behavioural changes that may not be routinely highlighted to parents at discharge. Several barriers to accessing prompt medical assistance were identified including parents feeling that their concerns were not taken seriously, long wait times and lack of protocols at A&E.
Conclusions Our study highlights behavioural symptoms as being a potentially underemphasised sign of deterioration and identifies a number of barriers to parents accessing support when they are concerned. It is important that parents are encouraged to seek advice at the earliest opportunity and that those health professionals at the front line have access to the information they need in order to respond in an appropriate and timely way. A role for home monitoring and making decisions about their child at an early stage to ensure that they receive appropriate and timely medical intervention.

What is already known
- Congenital heart disease accounts for 3% of infant mortality in the UK, with many children requiring major surgery in the first few days or weeks of life.
- Children with residual complex needs are often discharged to be cared for by their parents at home.
- These children often remain vulnerable to rapid deterioration, and therefore, it is essential that parents are able to identify symptoms of deterioration and access appropriate and timely medical intervention.

What this study adds
- Information given to parents is not always sufficient to enable them to make timely decisions about their child’s symptoms.
- Behaviour change was noted to be a sign of deterioration that may not be routinely discussed with parents.
- Local health professionals must have sufficient knowledge and information in order to respond quickly and appropriately to parent’s concerns.

BACKGROUND
UK congenital heart diseases (CHDs) audit data indicate that the number of operations in small infants with more complex CHDs such as hypoplastic left heart syndrome is increasing year-on-year, with more of them surviving the initial operation. Even after successful cardiac interventions and appropriate hospital recovery, some infants, particularly those with functionally univentricular hearts and those with associated medical conditions, remain fragile when they are discharged home. For example, UK audit data from two cardiac units for the years 2000–2009 found that 11% of neonates died within 30 days of surgery for CHD, but a further 7% died before their first birthday despite apparently successful surgery. Around half of these deaths occurred in the community or after unexpected emergency readmission. Babies discharged following palliative surgery that are awaiting subsequent staged surgeries can be particularly vulnerable to rapid deterioration, and this makes the role of parents particularly critical in recognising signs of deterioration in their child at an early stage to ensure that they receive appropriate and timely medical intervention.

To understand more about parent perspectives of caring for a child with complex needs after congenital heart surgery, we undertook a qualitative study involving semistructured interviews with parents. Our study aimed to describe the ways in which parents recognise and make decisions about their child’s symptoms, their experience of seeking help when there was a concern and any barriers they encountered when seeking help.

METHODS
Parents were invited to take part in the study if their child underwent major congenital heart surgery.
surgery in their first year of life at one of three UK children’s hospitals and subsequently died or were readmitted unexpectedly to intensive care following their initial discharge. Parents were invited to interview if their child had their index surgery in the last five years and were initially approached by specialist nurses who obtained consent to pass their details to the research team.

Interviews were conducted face-to-face by a single researcher (JT) and all but one took place in parents’ own homes. Parents were asked about caring for their child at home following surgery, support they received and events leading up to any emergency readmissions. Interviews were tape-recorded and transcribed verbatim before being analysed using Framework Analysis. Framework Analysis is a structured approach to managing qualitative data that aims to reduce bias and make analysis of large data sets more manageable. Analysis involves the construction of a series of ‘frameworks’ or grids into which summarised qualitative data are entered under descriptive headings generated by the research team after careful examination of the transcripts. Data from each transcript are entered into the framework, which are then used to extract key themes relevant to the research questions. In the development of frameworks for the present study, each transcript was read by at least three members of the research team.

RESULTS

Descriptive information

Specialist nurses contacted 25 families, 21 of whom agreed to be interviewed. One family was excluded as they did not meet inclusion criteria, leaving a total of 20 families who were interviewed for the study. Of these families, 11 were bereaved. Fourteen interviews were conducted with one parent alone (N=14 mothers), and six with both parents together. A range of ethnic, educational and socio-economic backgrounds were represented in the sample (see Table 1). One parent did not speak English as a first language and two were bilingual.

All children had their first surgery between September 2009 and October 2013. Following their initial surgery, 12 children were discharged home directly from the specialist surgical centre; the remainder were discharged to their local hospital in the last step-down arrangement. A case-by-case summary of complications and symptoms for each patient is provided in Table 2.

Data are presented in three sections. The first section (Symptoms) describes symptoms of deterioration noted by families, the second section (Decision-making about symptoms) focuses on decision-making about symptoms and the final section (Experience of seeking help) describes families’ experiences of seeking help. Additional quotes are presented in boxes 1–7.

Symptoms

No symptoms

A small number of families reported very mild or no obvious symptoms at all followed by the very sudden collapse and deterioration of their child. Two apparently non-symptomatic children were readmitted as a result of routine saturation and blood pressure monitoring, which identified a blocked shunt in one case and the imminent need for further palliative surgery in another.

Feeding and gastrointestinal symptoms

Many families noted changes in their child’s feeding behaviour, which included reduced feeding, increased lethargy during feeds and the presence or increase in vomiting. For many families, these symptoms came on gradually and presented in the context of challenging feeding behaviour characteristic of cardiac babies. In one case, a prolonged bout of diarrhoea following routine vaccinations the previous day resulted in the very rapid decline of a previously well child.

Respiratory distress

A variety of terms were used by parents to describe respiratory symptoms in their baby. These included descriptions of breath sounds such as ‘wheezing’, ‘grunting’, ‘straining’ and ‘whistle’; changes in the rate, pattern or work of breathing including ‘breathlessness’; or their child’s appearance such as flaring nostrils and recessing under the ribs, which was sometimes described by parents as an abdominal symptom.

Appearance

It was common for parents to describe changes in their child’s appearance. This included changes in colour around the lips and extremities, which in the earlier stages may have been transitory, appearing in ‘spells’ or during exertion. Interestingly, there was variation in the ways that parents described the colour of their child: ‘blue’, ‘purple’, ‘pale’, ‘grey’ and ‘yellow’. Some parents reported that the colour changes were so subtle that they either missed them completely or they were not apparent to anyone but them. Colour change sometimes presented in conjunction with cold extremities. Some parents also reported that their child had started to become more ‘sweaty’ or ‘clammy’, particularly at night or during a feed.

Behaviour

Many parents described behaviour changes in their child. These were typically subtle and not dissimilar to behaviours exhibited by healthy babies, which made them particularly difficult for parents to interpret. Sometimes these subtle behavioural changes were the sole indicator that the child was unwell. In the early stages of their child’s deterioration, several parents noticed their child becoming increasingly weak and lethargic and tiring more quickly during exertion or feeds. Some parents noted changes to their child’s sleep pattern with them sleeping more during the day and waking more frequently in the night.

Another early sign was their child being generally more ‘moody’, ‘grouchy’, ‘emotional’, ‘agitated’ or ‘unsettled’, and
<table>
<thead>
<tr>
<th>Identifier</th>
<th>Diagnosis</th>
<th>Complication</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>FR01</td>
<td>Single-ventricle disease (not HLHS)</td>
<td>Right diaphragm palsy with plication</td>
<td>Respiratory distress, Reduced feeding, ++vomiting, Abdomen ‘not quite right’ (respiratory distress)</td>
</tr>
<tr>
<td>FR02</td>
<td>HLHS</td>
<td>Wound infection (emergency sternal wound debridement)</td>
<td></td>
</tr>
<tr>
<td>FB03†</td>
<td>Transposition of the great arteries (plus or minus other features)</td>
<td>Out-of-hospital cardiac arrest (cause unknown)</td>
<td>Collapsed at home after a feed, No other symptoms</td>
</tr>
<tr>
<td>FB04†</td>
<td>HLHS</td>
<td>Sudden collapse at home. Died in A&amp;E</td>
<td>Excessive crying and screaming, Collapsed at home</td>
</tr>
<tr>
<td>FB05†</td>
<td>HLHS</td>
<td>Aspirated at home</td>
<td>Reduced feeding, ++vomiting, Dry nappy</td>
</tr>
<tr>
<td>FB06†</td>
<td>Ventricular septal defect plus significant medical comorbidity</td>
<td>Sudden collapse at home</td>
<td>Respiratory distress, Dark blue colouring, ++vomiting, Crying, Found in the night in respiratory distress</td>
</tr>
<tr>
<td>FR07</td>
<td>Single-ventricle disease (not HLHS)</td>
<td>Blocked left shunt (urgent redo)</td>
<td>Respiratory distress, Respiratory distress, Recessing chest,-purple fingertips and lips, Did not notice first time but symptoms pointed out at routine scan at local hospital</td>
</tr>
<tr>
<td>FR08</td>
<td>Tetralogy of Fallot</td>
<td>Blocked shunt (urgent central shunt)</td>
<td>No obvious symptoms, No obvious symptoms, Mother felt something was wrong but did not know what it was ‘mother’s instinct’</td>
</tr>
<tr>
<td>FR09</td>
<td>Transposition of the great arteries (plus or minus other features)</td>
<td>Resection of aortic aneurysm</td>
<td>No obvious symptoms, No obvious symptoms</td>
</tr>
<tr>
<td>FB10†</td>
<td>Single-ventricle disease (not HLHS) and significant medical comorbidity</td>
<td>Aspirated at home</td>
<td>Breathing, Pale colouring, ++vomiting, Crying, Found in the night in respiratory distress</td>
</tr>
<tr>
<td>FB11†</td>
<td>HLHS</td>
<td>Sudden collapse at home. Died in A&amp;E</td>
<td>Excessive crying, Unable to settle</td>
</tr>
<tr>
<td>FB12†</td>
<td>Single-ventricle disease (not HLHS)</td>
<td>Blocked shunt</td>
<td>Breathlessness noted by paediatrician 2 days before, appeared ‘normal’ to parents, Sleepier after feeds, Screaming and unable to comfort, Collapsed at home</td>
</tr>
<tr>
<td>FB13†</td>
<td>HLHS</td>
<td>Blocked shunt</td>
<td>No obvious symptoms, Routine vaccinations day before and following this, More lethargic than usual, Diarrhoea in night, Deteriorated over the course of the day, Respiratory distress -&gt;collapsed at home</td>
</tr>
<tr>
<td>FB14†</td>
<td>Anomalous coronary artery from pulmonary artery</td>
<td>Sudden collapse at home. Died in A&amp;E</td>
<td>Sweating+++ and vomiting after feeds, ‘Spelling’ intermittently (pale/blue/grey lips), Quiet and weak in the AM, Grunting/straining sounds, Started screaming during feed and collapsed</td>
</tr>
<tr>
<td>FR15</td>
<td>Single-ventricle disease (not HLHS)</td>
<td>Severe mitral regurgitation and left ventricular failure</td>
<td>Reduced appetite, Lethargic, Vomiting, Cough, ‘Grunting’ breath sounds</td>
</tr>
<tr>
<td>FR16†</td>
<td>Single-ventricle disease (not HLHS)</td>
<td>Pacemaker pocket infection and dehydration</td>
<td>+++crying and restless at night, Rapid breathing, Blue face/hands/lips, Recessing under ribs</td>
</tr>
<tr>
<td>FB17†</td>
<td>Single-ventricle disease (not HLHS)</td>
<td>Sudden collapse at home. Died in A&amp;E</td>
<td>Appeared ‘agitated’ and generally less settled, Taking less feed in one go, Slight cough, Routine vaccinations week prior to death.</td>
</tr>
</tbody>
</table>
Box 1  Selected quotations from parents whose child showed no obvious symptoms of deterioration

"The whole thing of, 'You will know when your child is so unwell.' Well, clearly he deals with it pretty well." (FR09)
"Everything was normal, literally, until the morning that we lost her." (FB12)
"She was absolutely fine, she was feeding, she was doing everything that we needed her to do, and she was kind of growing nicely. So I think it came as a bit of a shock." (FR19)

generally ‘not themselves’. Parents described babies that cried more frequently and were more difficult to comfort than usual. The changes they described were not out of keeping with what would be expected for a healthy baby but they were unusual for their own child. Several parents found this very difficult to interpret and described a feeling of knowing something was wrong but being unable to identify what it was. In the later stages, a number of parents reported these behavioural symptoms increasing dramatically into persistent crying followed by high-pitched ‘screaming’ that preceded their child’s rapid deterioration.

Decision-making about symptoms

While many, but not all, parents recalled being given information about signs and symptoms during their child’s hospital admission, this was not always sufficient to enable them to recognise these symptoms out in the community. Even when symptoms were recognised, parents sometimes struggled to describe these and to make decisions about a course of action. This was particularly true if symptoms appeared very subtle or had a gradual onset. One parent commented that as this was her first child she found it difficult to evaluate symptoms as she did not know what was ‘normal’ for a healthy baby. Several parents spoke of the burden of completing monitoring forms at home, particularly in relation to feeding, with one parent explicitly stating that she felt she may have missed early warning signs in her child as a result. There was also some difficulty identifying change when the child’s baseline was atypical. A small number of parents said that they did not recognise the symptoms on the first occasion, but that once these had been pointed out to them on their own child, they found it much easier to identify them on subsequent occasions.

Decision-making about symptoms took place in the context of local services that were relatively unfamiliar with CHD and, in some cases, this had a detrimental effect on parents’ trust in their local hospital. Despite this, some families still recognised the need for their child to be known to local services.

Experience of seeking help

For symptoms that parents judged to be non-urgent, their first point of contact would typically be the health professional with whom they had the best relationship—often the cardiac liaison nurse at their specialist centre or the community nurse. However, in some cases, parents waited until their next

Box 2  Selected quotations from parents describing feeding and gastrointestinal symptoms in their child

"The last week of her life, she started being sick and she’s never been sick. And I said to the community nurse “she’s been a bit sick and she’s not bringing up her wind…There’s something wrong.” (FB05)
"He was sick the whole time. He couldn’t drink a bottle without being sick.” (FR09)
"I think it was around that time he started to take off his feeds as well.” (FB17)
"One thing we did notice was that if it was quite a hot day, he would be a bit sick.” (FB18)
follow-up appointment to discuss their concerns with their local paediatrician or their cardiologist, resulting in a delay in their child receiving treatment. Several parents mentioned fear of paediatrician or their cardiologist, resulting in a delay in their follow-up appointment to discuss their concerns with their local health professionals, although this could be countered by positive experiences of seeking help and reassurances at an early stage—typically from the liaison nurse—that they should phone with any concern no matter how small.

Parents reported an overwhelmingly positive experience of the support they received from their cardiac liaison nurse with this link being described by one family as a ‘lifeline’. This was particularly true if this was someone they had met during their hospital admission. In some cases, the liaison nurse was able to liaise with a family’s local hospital to facilitate more rapid access and treatment in an emergency, discuss treatment plans with local health professionals and arrange transport back to the specialist centre when required.

Not all families had a good experience of seeking help and several families felt their concerns were not taken seriously by their local hospital to facilitate more rapid access to care. Out-of-hours service at A&E was also raised by some parents, with many detailing long wait times and one parent describing having to make decisions about the severity of her child’s symptoms within working hours in order to get the best care.
**Box 6** Selected quotations illustrating parent’s decision-making about their child’s symptoms

“We just said [baby] just needs to be known, that’s all it is, just get known because if you present him in an iller condition, he’s deteriorating, they need a baseline to compare it against.” (FR01)

“It felt like total care to none at all.” (FB11)

“I think that was the problem in the end because I was so focussed on the paperwork than actually my baby, I couldn’t see what else was going on with her because I was so worried about every drop of milk.” (FB05)

“That’s the first time I’d seen anything like that, so I wasn’t really aware of what was going on until they said, “well okay, this is the kind of stuff you need to look for…I think once you’ve seen it once you can tell after that.” (FR07)

“When I really feel strongly about something I just have to act on it and I need to take him to see someone and then I can go, ‘Look, I just think that there’s something wrong here. Help me out, because I can’t tell you what it is.” (FR09)

“They told you what to look out for, his blue lips and his eyes, but I think from a parent point of view, you do not really see it as much as a medic would.” (FB11)

“I think it’s quite hard if it’s a gradual thing. To this day I still don’t really know whether she was more breathless or not, but she was her normal usual self.” (FB12)

**DISCUSSION**

Our study details parent accounts of making decisions about their child’s symptoms at home after congenital heart interventions in the first year of life and their experiences of seeking help. Our findings suggest that, while the potential for post-discharge deterioration in these children is well known, information given to parents is not always sufficient for them to make decisions about their child’s symptoms and summon appropriate support. One difficulty is in the language used to describe symptoms to parents. For example, some classic descriptions of heart failure describe ‘blue’ skin colour, which several parents in our study found ambiguous and difficult to interpret. Decision-making may be particularly challenging if symptoms appear gradually or if parents have no previous experience of seeing their child unwell. Behavioural symptoms, such as changes in sleep pattern, lethargy, crying and irritability, were also highlighted as a potentially under-recognised sign of deterioration in these children. These symptoms were difficult to interpret as they often presented subtly at first and could be difficult to distinguish from behaviour typical of a healthy infant. It is important that parents are encouraged to seek advice at the earliest opportunity and that health professionals at the frontline have access to the information they need to respond in an appropriate and timely way. We suggest that such subtle signs as a behaviour change should be considered within the wider context of an infant’s medical history, ‘normal’ clinical state and physical examination at a given time point, since these may represent an early warning of true deterioration.

While it is important for parents to be trained to recognise symptoms of deterioration in their child, it is also important that they are able to summon prompt and appropriate medical care when they have a concern. Barriers to accessing such assistance included parents’ fear of appearing ‘silly’ or ‘paranoid’, feeling their concerns were not taken seriously, and long wait times and lack of protocols at A&E. Several parents described feeling let down by their local services after flagging symptoms of concern and either being falsely reassured or advised to wait until their next follow-up to speak with their child’s cardiologist. Protective factors included parents having a trusted point of contact with whom they could safely discuss their concerns, and having the confidence to assert themselves with health professionals when they were not satisfied that these had been addressed. A role for home monitoring was also noted as potentially useful in identifying high-risk children. In some cases, apparently asymptomatic children were identified with the aid of measurements taken at routine follow-up, suggesting that these more objective forms of surveillance may be effective for identifying children who require intervention but appear clinically well.

Our study has a number of limitations. First, parents approached to take part in the study were those known to specialist nurses who assisted with recruitment. While this meant that parents were approached by someone familiar to them resulting in a high opt-in rate, it is possible that families opting into the study were those who had a better relationship with the nurses at their hospital. An important consideration of qualitative research methods is to describe, rather than quantify, the views held by a population of interest; therefore, it is important to ensure that the study sample represents the diversity present...
in the population being described. Our study included parents of children with a range of diagnoses, outcomes and discharge pathways. We also attempted to achieve diversity in our sampling of ethnicity and parent educational level, although, as is often typical in UK research, our sample included parents of predominantly white British children. Our recruitment strategy was also not optimised to recruit parents whose first language was not English, despite offering access to interpretation, and it is likely that these parents face additional challenges not captured by this study.

Many complications that arise following congenital heart surgery can lead to relatively rapid deterioration in a small infant leaving a small window of opportunity to intervene. This makes it particularly important for parents to be supported to recognise symptoms in their child and for them to be able to summon help quickly when there is a concern. The family burden of caring for a child with complex health needs is well known, and since families responding to their infant’s symptoms are likely to be acting under stress, it is important that the information they are provided with is straightforward and that help is readily accessible. Our study has implications for health professionals involved in the discharge and follow-up of babies after congenital heart surgery, both in relation to interpretation of reported symptoms and the processes they follow in response.

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Contributors JF was involved in the development of the interview schedule and conducted all parent interviews for the study, anonymised transcripts, prepared qualitative frameworks, was involved in the analysis and in preparation of the manuscript for submission. LS was involved in recruitment of the families, interpretation of the findings and commented on drafts of the manuscript. CB, KB, RLK and JW were involved in the design of the study, development of the interview schedule, read anonymised transcripts, participated in the analysis and commented on earlier drafts of the manuscript. In addition, JW oversaw the day to day running of the data collection. SC read anonymised transcripts, participated in the analysis and contributed to earlier drafts of the manuscript.

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Competing interests None declared.

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Signs of deterioration in infants discharged home following congenital heart surgery in the first year of life: a qualitative study

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