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Making things better for parents when babies need surgery

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Making things better for parents when babies need surgery

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ABSTRACT

(i) Objectives

To understand the experiences of parents of infants who required surgery early in life. To identify messages and training needs for the extended, clinical teams caring for these families – including paediatric surgeons, neonatologists, nurses, obstetricians, midwives and sonographers.

(ii) Setting

United Kingdom wide interview study, including England, Wales and Scotland.

(iii) Participants

In-depth narrative interviews were conducted with 44 parents who had a baby who underwent neonatal surgery. Conditions included those diagnosed antenatally (e.g. exomphalos, gastroschisis, congenital diaphragmatic hernia) or which developed postnatally (e.g. Hirschsprung's disease, necrotising enterocolitis). Interviews were video and audio recorded and analysed using a modified grounded-theory approach.

(iv) Results

While some parents reported experiencing excellent communication and felt they were listened to and involved by the care team, this was not always the case. Dealing with large, complex medical and surgical teams could result in conflicting messages, uncertainty and distress. Parents wanted information but also described being overwhelmed and wanting to distance themselves to maintain hope. Information and support from other parents in hospital and online groups was highly valued. Of particular concern was support for going home and caring for their baby after discharge; an open access policy for readmission offered a helpful safety net. The writings of Bourdieu could have resonance in interpreting

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3 the experiences of parents as they enter the world of highly-technical neonatal medicine
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5 and surgery and the knowledge of the professionals who work in these environments.
6

7 (v) Conclusions

8
9 Listening to the experience of parents provides rich data to enhance clinical understandings
10
11 on how to improve information and communication with parents, and ameliorate the deep
12
13 and lasting distress and anxiety that some parents feel when their infants face early surgery.
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16 Article Summary

17 Strengths and Limitations

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22 • This is a UK based study that sought to explore the experiences of parents who have
23
24 an infant requiring surgery in the first year of life. Interview studies in this field are
25
26 rare and our study provides rich insights into the emotional and practical impacts of
27
28 these experiences.
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31 • While the interviews could not cover all possible conditions, they provide insights
32
33 that may be generalisable across many different surgical procedures/medical
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35 conditions.
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38 • A prenatal diagnosis of a congenital anomaly is associated with high levels of
39
40 maternal psychological distress. Entering the complex environment of a neonatal
41
42 intensive care unit is emotionally challenging for new parents
43
44
45 • Parents of children undergoing early surgery value being involved in care and
46
47 decision-making; regular communication is an essential part of this.
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49
50 • Clinicians should support and facilitate peer interactions both in person and through
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52 social media, as these are a vital source of support for many parents.
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INTRODUCTION

The experiences of parents of infants who undergo surgery in the first year of life are rarely recorded. Even after discharge from hospital, these infants may require multiple outpatient visits to different specialist clinics and their ongoing care requirements can have significant effects on the quality of life of parents and existing children, as well as economic effects through lost work days.

Many of these infants will require surgery because of a gastrointestinal congenital anomaly, such as exomphalos, gastroschisis or Hirschsprung's disease. These conditions are under-researched¹, understanding of them is poor and interventions are rarely based on robust evidence. Routine sources of information are limited.² Outcomes for infants with rare anomalies are improving^{3 4} and the need for rigorous research into surgical and clinical outcomes is paramount.² Alongside this, understanding the impact of these diagnoses and surgical treatments on parents and families is central to their long-term recovery.

There is little research on parent experiences of conditions that require early surgery. However, we can supplement this limited evidence base by drawing on research into parent experiences of congenital heart disease and surgery and more generally research about parents' experiences of neonatal intensive care units. The literature here points to the practical and psychological impact on families^{5 6} and the importance of good communication between parents and staff.⁷ Parents of children with congenital heart disease are at high risk for mental health morbidity, experiencing stress, depression, anxiety and traumatic stress responses⁸⁻¹² and the cost implications are profound.¹³ Parents

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2
3 experience difficulties with bonding and breastfeeding while their infants are in hospital^{8 14}
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5^{15 16}and their infants' complex needs after discharge.¹⁷
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10 Mothers of infants in neonatal intensive care face emotional challenges as they seek to find
11 a role for themselves in medically complex environments with perilously ill infants.¹⁸
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14 Wilkinson¹⁹ and others have explored the contentious ethical issues facing those who care
15 for critically ill infants and the extent to which parents should be involved in decision-
16 making. Little is known about the relationship between quality of mother-child interaction
17 and child development after major neonatal surgery or intensive care, but the parental
18 mental health and familial environment are thought to be vital to the recovery and mental
19 well-being of the infant.²⁰⁻²²
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29 **Theoretical framework**

30
31 One approach to thinking about these experiences could be to draw on the writings of the
32 French sociologist Pierre Bourdieu whose work focused on examining experiences of social
33 class and the production of knowledge and power^{23 24}. One of his key concepts was the
34 notion of 'habitus', whereby individuals share their history and environment with others
35 who have similar positions, producing a 'stylistic affinity' and where 'social identity is
36 defined and asserted through difference'. Habitus is the way one unconsciously acts,
37 interacts and behaves within the social world in a 'taken for granted' manner, according to
38 socialised norms, traditions and unwritten rules of particular groups. Bourdieu also wrote
39 about various forms of capital, qualities that establish social standing within a particular
40 habitus or social setting. Capital is used to provide increased access to various resources
41 within the field concerned (in this case neonatal care and surgery) and power is derived
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3 from configurations of these types of capital²⁵. Although his writings focused on class
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5 lifestyles and social identity, these ideas could have resonance in interpreting the
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7 experiences of parents as they enter the world of highly-technical neonatal medicine and
8
9 surgery and the knowledge of the professionals who work in these environments²⁶.
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13
14 The aim of this qualitative study was to: explore parents' experiences and perspectives of
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16 having a baby who needs surgery; identify the questions and problems that matter to
17
18 parents during and after their pregnancy and infant's surgery; and identify the long-term
19
20 impact on parents and families. In this article, we report on immediate actions that can be
21
22 implemented to rapidly improve parent experience.
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25 26 27 28 METHODS

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30 We conducted interviews with 42 parents, all of whom had an infant who needed surgery in
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32 the first year of life. Parents were recruited from England, Scotland and Wales and included
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34 those for whom the experience was very recent through to parents whose son was 25 years
35
36 old. Most parents' infants were still living, but we interviewed the parents of one boy who
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38 died aged seven months. Conditions included exomphalos, gastroschisis, congenital
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40 diaphragmatic hernia, Hirschsprung's disease, inguinal hernia, atresia (jejunal and
41
42 oesophageal) and necrotising enterocolitis (see Table 1). Parents were interviewed either
43
44 individually or in pairs. Recruitment was through support groups, paediatric surgeons,
45
46 neonatal nurses, other specialists and word of mouth. We aimed for a maximum variation
47
48 sample and continued interviews until thematic saturation was reached. All interviews were
49
50 conducted by LH, in participants' own homes, or in a venue of their choice. Interviews were
51
52 video or audio recorded and fully transcribed. We undertook analysis of the transcribed
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2
3 interviews using an interpretive approach to thematic analysis.^{27 28} Interview transcripts
4
5 were coded by LH using a framework which was developed iteratively and reflected both
6
7 anticipated and emergent themes. Coding reports were then analysed separately by LH and
8
9 LL; any differences in interpretation were then discussed. MK and AML reviewed
10
11 summarised findings and contributed a further clinical layer of analysis
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16 **Ethics Committee Approval:** Ethics committee approval was given for this study by the
17
18 Berkshire Ethics Committee, 09/H0505/66. All participants gave informed consent before
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20 taking part and have given written consent to their interview data being included in
21
22 publications.
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28 RESULTS

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30 Some parents discovered there was a problem with their baby during antenatal scans,
31
32 others not until after their baby had been born. Regardless of when the diagnosis came,
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34 parents of a baby who needs surgery faced many challenges over the ensuing months and
35
36 years.
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42 The care pathways for these infants were often long and complex. Setbacks were common,
43
44 and at no point could clinical staff give parents any guarantees. The practical and emotional
45
46 uncertainties were, therefore, huge. Living with uncertainty and worry was something
47
48 parents had to get used to, at every stage.
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53 *"It was always a waiting game and tricky because you want to know the answer, 'When is*
54
55 *my baby going to come home?'"* (O2, daughter with gastroschisis)
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5 “We just don’t know what road he is going to take.” (20/21, son with Hirschsprung’s
6 disease)
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11
12 Large and complex teams of staff across many different specialities were involved in looking
13 after these infants over weeks, months and years. Our interviews highlighted some key
14 steps that could improve the experience for parents. These do not so much focus on the
15 surgery itself, but on the care and support parents are given before and after.
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- 23 i) Communication
 - 24 ii) Managing information and information overload
 - 25 iii) Encouraging parents to seek out others (online, hospital groups)
 - 26 iv) Help in finding a role
 - 27 v) Preparing for going home
 - 28 vi) Open access policy
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44 **Communication**

45 Communication with the various health professionals looking after their baby was central to
46 parents’ experiences. These professionals spanned many disciplines – neonatologists,
47 surgeons, but also paediatricians, intensive care nurses, specialist stoma nurses and other
48 specialists further along, such as physiotherapists or nutritionists.
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3 The babies were often very sick with a rare condition and receiving complex medical and
4
5 surgical treatments. Parents often felt isolated and struggled to find information about their
6
7 baby's condition. Communication about how their baby's progress and the treatment plan
8
9 was therefore very important.
10

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14 There were often extended periods of uncertainty as doctors were not able to answer
15
16 parents' questions. While these periods were a challenge to parents, there were examples
17
18 of good, clear communication which really helped at a stressful, frightening time.
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24 i) Being kept up to date

25
26 Being kept up to date with their baby's care was important to parents, especially when
27
28 plans changed. They valued the opportunity to ask questions repeatedly. ID25 said she was
29
30 constantly asking questions but staff were very good at answering them all and reassuring
31
32 her. (see Box 1)
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34

35
36
37 ii) Communicating well

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39
40 Although health professionals often had to deliver bad news, there were many examples of
41
42 good practice in managing this well. These interactions were characterised by giving parents
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44 information in a clear, accessible manner, sometimes supported by drawing diagrams, but
45
46 without patronising/'dumbing down'. Parents appreciated doctors and nurses taking time
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48 to answer their questions, not making them feel that any question was a silly one.
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iii) Conveying expertise

When infants were in hospital for long periods, relationships of mutual respect between parents and healthcare professionals were hugely valued. As one mother explained, “you are handing over the most precious thing to this person who is going to put them under anaesthetic and disappear into an operating theatre with them and you hope their gonna come out the other side. So you have to have that level of assurance.” She and her husband were reassured by their surgeon’s “confidence not arrogance”. Others talked about the importance of trust and feeling as though their baby was in expert hands, cared for by clinicians who were knowledgeable about their condition.

iv) Being listened to and feeling part of the team

While parents recognised that they relied on doctors’ expertise and judgement in planning their baby’s care, they really valued feeling involved in their baby’s care – “part of it, part of that team”.

Managing information and information overload

Understanding the diagnosis and possible journey ahead can be overwhelming for parents.

Parents often felt powerless, both during pregnancy and once their baby had been born.

Information – about the condition and procedures but also other parent experiences – was crucial in helping parents come to terms with the diagnosis. Seeking out information played a central role, helping parents feel they were actively doing something for their baby and

1
2
3 family. ID01's son had exomphalos. Seeking information felt like the only thing she and her
4
5 husband could do. *"We were powerless to change anything other than lots of information"*.
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10 However, there were also dangers of information overload. Parents could find it hard to
11
12 take on board a great deal of complex information at once, and needed time to understand
13
14 and process what was happening to their baby. On the whole, parents said the information
15
16 given by hospitals was not sufficient and they supplemented it with their own background
17
18 reading and research. Pointing parents in the direction of trusted sources of information
19
20 would have been a key easy action to help them.
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22

23 24 25 26 **Encouraging parents to seek out others**

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28 Finding support from other parents who had been through similar experiences (either
29
30 online or face to face) was described as a crucial factor in helping parents cope and
31
32 understand more about their baby's diagnosis. Staff can encourage and facilitate this
33
34 through introducing parents to each other, or suggesting online support groups. One unit
35
36 had established a popular and thriving Facebook support group for parents of babies with
37
38 Hirschsprung's disease.
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45 46 **Helping parents find a role**

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48 Parents often described how "useless" or "helpless" they felt not being able to do anything
49
50 for their baby while in hospital. Yet when they went home they were going to become
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52 experts in their baby's care. Helping them bridge this gap was an area where staff could
53
54 make a real impact.
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3 In the early days, spending time at their baby's side was all many parents felt they could do.
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5 They looked for small ways they could regain a sense of control and get involved in their
6
7 baby's care. While it was not always practical in critical care environments, parents
8
9 appreciated helping with feeding, bathing, singing and talking to their baby where possible.
10
11 After three weeks, ID02 was able to hold her daughter for the first time, "*it was like*
12
13 *Christmas*". Supporting mothers to either breastfeed or, more often, express milk for their
14
15 baby, was another way of parents bonding and being involved in their baby's care. Some
16
17 parents described how they were supported and encouraged to become "experts" in
18
19 aspects of their baby's daily care – changing dressings or stoma bags. Activities like these
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21 were key to bridging the gap between hospital and home.
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28 **Preparing to go home**

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30 After weeks or months in hospital, being able to bring their baby home was a huge step for
31
32 many parents. While a positive sign that their baby was on the mend, it could also be
33
34 daunting to leave the "safety net" of hospital and clinical expertise. Some parents described
35
36 handover or normalisation programmes as very helpful in preparing them technically and
37
38 emotionally for caring for their infant at home. Parents were trained in some of the skills
39
40 they would need (wound management, stoma care, first aid, resuscitation) and given the
41
42 opportunity to 'room in' with their baby for a few nights before going home.
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49 **Open access policy**

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51 Accessing hospitals and specialists after their baby had been sent home could be challenging
52
53 for parents, especially if home was a distance from the specialist surgical centre. When
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55 problems came up, as they often did, it was hard to know where to take their baby. So being
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3 given open or emergency access back to the team who had looked after their baby, without
4
5 having to go through A&E first, was really valued by parents.
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10 DISCUSSION

11
12 This study adds valuable insights into the support and information needs of parents when
13
14 their baby requires neonatal surgery. These surgical journeys are often a long haul for baby
15
16 and parents. Our study highlights the importance of clear and ongoing communication
17
18 between parents and the often large, multi-disciplinary teams caring for their infant and
19
20 points to immediate actions that can improve parent experiences and outcomes. Parents
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22 value being listened to, encouraged to be a part of the care team and supported in finding a
23
24 role for themselves. They need information from the professionals caring for their infant but
25
26 also recommendations of good sources of information to supplement their knowledge,
27
28 while being mindful of information overload. For some, encouraging them to seek support
29
30 from other parents is of great value.
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38 Previous work exploring parents' experiences of having an infant in NICU or surgery has
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40 highlighted the importance of good communication and emotional support, giving parents
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42 support at handover for surgery and pointed to the impact of scanty and infrequent
43
44 information giving.^{7 29} Parents experiences are not only affected by their baby's diagnosis
45
46 and care, but also the ways in which services are organised to support families to navigate
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48 the systems and maintain a new 'second campus' as they look after their baby and continue
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50 their lives outside the hospital.³⁰
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3 Involving and supporting parents is increasingly recognised as an important component of
4 providing holistic paediatric care and can help with the uncertainty of parenting an infant
5 during critical illness. Parent experiences of NICU point to the vital role that neonatal nurses
6 have in engaging with mothers and the importance of that relationship.³⁰ Aagaard⁵
7 discussed the importance of trying to strengthen maternal competence, and suggested
8 parent-nurse chat as a communication strategy. Our findings provide examples of the ways
9 in which encouraging parents to be involved with infant can be achieved.
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21 Others have described the role of the expert parent³⁰ and home monitoring programmes
22 after cardiac surgery.^{17 31} Studies have indicated that parents are not adequately prepared
23 for discharge and are not well equipped to recognise deterioration in their child. The
24 positive examples of being prepared for discharge and supported in becoming the primary
25 carer offer insights into how parents might be supported to manage this transition.
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35 Bourdieu's theoretical concepts of habitus and capital are helpful in exploring and
36 unpacking the experiences of parents in these highly technical environments and the value
37 they place on communication, finding their own role and seeking out other parents. They
38 travel a journey from being newcomers in an environment (neonatal/surgical unit) where
39 they are unfamiliar with the socialised norms. They have little capital and no idea how to
40 'play the game' (what Bourdieu termed the logic of practice) and negotiate the field. There
41 is initially an unequal balance of power. But over time, assisted by good communication
42 from the health professionals and the networks of support and information provided by
43 other parents, parents develop confidence and competency which Bourdieu might have
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3 interpreted as social capital. By the time they take their infants home these parents are well
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5 on the way to becoming technical experts in their baby's illness and care.
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10 STRENGTHS AND LIMITATIONS

11 This is a UK based study that sought to explore the experiences of parents who have an
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13 infant requiring surgery in the first year of life. Interview studies in this field are rare and our
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15 study provides rich insights into the emotional and practical impacts of these experiences.
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17 While the interviews could not cover all possible conditions, they provide insights that may
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19 be generalisable across many different surgical procedures/medical conditions.
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26 CONCLUSION

27 As babies recover, the potential for parental expertise grows. Our study highlights the vital
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29 role of information, both about the condition and about the infant's progress. Health care
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31 staff could discuss or direct parents to information sources, seek to empower parents
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33 through involving them with their infant's care where possible, and link them with other
34
35 parents.
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42 **A Contributorship statement** The study was conceived by MK. All interviews were collected by
43 LH. Analysis was undertaken by LH and LL, with input from MK and AM. LH wrote the article, with
44 input from the other authors.
45

46 **B Competing Interests** Authors declare no competing interests
47
48

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3 **D Data Sharing statement** Participants were invited to review their transcript and mark any
4 sections that they did not want used before transferring copyright to the University of Oxford for use
5 in research, teaching, publications and broadcasting. These carefully anonymised transcripts form
6 part of a University of Oxford archive which is available to other bona fide research teams for
7 secondary analysis. All authors had access to the all of the data in the study and take responsibility
8 for the integrity of the data and the accuracy of the data analysis.
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Table of Participants

Table 1 Participants			
Condition	Identifier	Sex of child	Child's age at interview
Exomphalos	01	m	18 months
	02	f	6 years
	03	f	8 years
	04/05	f	8 years
	12/13	m	25 years
	16/17	m	13 years
	19	f	16 months
Necrotising Enterocolitis	41/42	m	Died age 7 months
	08	m	9 months
	09	m	11 months
	23	m	6 months
Hernia	26/27	f	9 months
Congenital Diaphragmatic Hernia	10/11	m	9 months
	15	m	5 years
	24	m	9 years
Hirschprung's Disease	18	f	1 year
	20/21	m	4 months
	22	m	16 months
	28/29	m	19 months
	39/40	m	5 years old
	43/44	m	5 years old
Gastroschisis	30	m	7 ½ months
	31	m	4 years
	32	f	3 years
	33/34	m	3 months
	36	f	19 months
	37	f	6 years
Short Bowel	35	f	7 years
Jejunal atresia	25	f	4 months
Oesophageal Atresia with trachea-oesophageal fistula	38	m	19 months
Undiagnosed	14	m	6 months

BOX 1**Communication**

"If you're in the dark that's when people would worry [...] as long as you, you know, either good or bad, what was going on and a lot of the things you ask them they don't know the answer because it's a time will tell kind of answer, but so long as someone tells you the time will tell sort of answer you've got an answer." (ID25, daughter with jejunal atresia)

Being kept up to date

"[I] probably annoyed the hell out of them, but wanted to know, OK, when he does this what is his next step, what has progressed to, how long will he be doing that and how long will it take and things." (ID15, son with CDH)

Communicating well

"I quite like things in a lot of detail so that when doctors are talking to you sometimes they can do stupid talk because they don't know how much you know medically, but I like to hear all of it and I don't want broken down terms, I want medical terms because then I can go and look up what the medical terms are, see what it's all about." (ID25, daughter with jejunal atresia)

Conveying expertise

"They've got this under control, they really know what they are doing." (ID26, daughter with ovarian hernia)

"I will trust you to the ends of the world" (ID38, describing the neonatal nurse who looked after her son with Oesophageal Atresia with trachea-oesophageal fistula)

Being listened to and feeling part of the team

"They've been very understanding and patient and I think recognising as well our role as parents and, that we, you know, have opinions and experiences, and not devaluing what we've learnt from other places as well." (ID01, son with exomphalos)

"I would say 99.9% of the time we've been treated really well, like human beings, not just numbers, and that has made an enormous difference to the experience as a family." (ID03, daughter with exomphalos)

Encouraging parents to seek out others

"It just makes it a bit real, you know, that you aren't the only one". (ID22, son with Hirschsprung's disease)

"Find parents, my absolute number one thing." (ID01, son with exomphalos)

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4 *"That was my number one support during that time with all these other mums who'd gone*
5 *through it."* (ID02, daughter with gastroschisis).
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8 **Helping parents find a role**

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10 *"I think you're so wrapped up in the medical needs of your baby and hoping that they're*
11 *going to be alive at the end of it that I just...hadn't anticipated that the little things would*
12 *be the things that matter, it would be the 'mummy' things that had been so easy to do*
13 *with my other children, they would be the things that would matter that I missed out on."*
14 (ID19, daughter with exomphalos).
15

16
17 **Preparing to go home**

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19 *"You're totally encouraged to do as much care for your baby as you can. It's your baby,*
20 *they're there to support you and to medically [um] jump in if, if need be, but don't expect*
21 *that they're there to feed and care for your baby because that's your job."* (ID34, son with
22 gastroschisis)
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21 *that they're there to feed and care for your baby because that's your job."* (ID34, son with
22 gastroschisis)
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	24	m	9 years
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	22	m	16 months
	28/29	m	19 months
	39/40	m	5 years old
43/44	m	5 years old	
Gastroschisis	30	m	7 ½ months
	31	m	4 years
	32	f	3 years
	33/34	m	3 months
	36	f	19 months
	37	f	6 years
Short Bowel	35	f	7 years
Jejunal atresia	25	f	4 months
Oesophageal Atresia with trachea-oesophageal fistula	38	m	19 months
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BMJ Open

What can make things better for parents when babies need abdominal surgery in their first year of life? A qualitative interview study in the United Kingdom

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What can make things better for parents when babies need abdominal surgery in their first year of life? A qualitative interview study in the United Kingdom

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ABSTRACT

(i) Objectives

To understand the experiences of parents of infants who required surgery early in life. To identify messages and training needs for the extended clinical teams caring for these families – including paediatric surgeons, neonatologists, nurses, obstetricians, midwives and sonographers.

(ii) Setting

United Kingdom wide interview study, including England, Wales and Scotland.

(iii) Participants

In-depth semi-structured narrative interviews were conducted with 44 parents who had a baby who underwent early surgery. Conditions included those diagnosed antenatally (e.g. exomphalos, gastroschisis, congenital diaphragmatic hernia) or which were detected postnatally (e.g. Hirschsprung's disease, necrotising enterocolitis). Interviews were video and audio recorded and analysed using a modified grounded-theory approach.

(iv) Results

While some parents reported experiencing excellent communication and felt they were listened to and involved by the care team, this was not always the case. Dealing with large, complex medical and surgical teams could result in conflicting messages, uncertainty and distress. Parents wanted information but also described being overwhelmed and wanting to distance themselves to maintain hope. Information and support from other parents in hospital and online groups was highly valued. Of particular concern was support when going home and caring for their baby after discharge; an open access policy for readmission offered a helpful safety net.

(v) Conclusions

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3 Listening to the experience of parents provides rich data to enhance clinical understandings
4
5 on how to improve information and communication with parents, and ameliorate the deep
6
7 and lasting distress and anxiety that some parents feel when their infants face early surgery.
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10 We suggest that the writings of Bourdieu could have resonance in interpreting the
11
12 experiences of parents as they enter the world of highly-technical neonatal medicine and
13
14 surgery and the knowledge of the professionals who work in these environments.
15

16 Article Summary

17 Strengths and Limitations

- 18
19 • This is a UK based study that sought to explore the experiences of parents who have
20
21 an infant requiring surgery in the first year of life.
22
23
- 24 • Interview studies in this field are rare and our study provides rich insights into the
25
26 emotional and practical impacts of these experiences.
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- 29 • While the interviews could not cover all possible conditions, they provide insights
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31 that may be generalisable across many different surgical procedures/medical
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33 conditions.
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40 INTRODUCTION

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42 The experiences of parents of infants who undergo surgery in the first year of life are rarely
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44 recorded. Even after discharge from hospital, these infants may require multiple outpatient
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46 visits to different specialist clinics and their ongoing care requirements can have significant
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48 effects on the quality of life of parents and existing children, as well as economic effects
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50 through lost work days.
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3 Many of these infants will require surgery because of a gastrointestinal congenital anomaly,
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5 such as exomphalos, gastroschisis or Hirschsprung's disease. These conditions are under-
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7 researched¹, understanding of them is poor and interventions are rarely based on robust
8
9 evidence. Routine sources of information are limited.² Outcomes for infants with rare
10
11 anomalies are improving^{3 4} and the need for rigorous research into surgical and clinical
12
13 outcomes is paramount.² Alongside this, understanding the impact of these diagnoses and
14
15 surgical treatments on parents and families is central to their long-term recovery.
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21 This study was conducted as an adjunct to the British Association of Paediatric Surgeons
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23 Congenital Anomaly Surveillance System (BAPS-CASS) and was focused on parents'
24
25 experiences of abdominal surgery. There is little research on parent experiences of
26
27 conditions that require early abdominal surgery. However, we can supplement this limited
28
29 evidence base by drawing on research into parent experiences of congenital heart disease
30
31 and surgery and more generally research about parents' experiences of neonatal intensive
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33 care units. The literature here points to the practical and psychological impact on families^{5 6}
34
35 and the importance of good communication between parents and staff.⁷ Parents of children
36
37 with congenital heart disease are at high risk for mental health morbidity, experiencing
38
39 stress, depression, anxiety and traumatic stress responses⁸⁻¹² and the cost implications are
40
41 profound.¹³ Parents experience difficulties with bonding and breastfeeding while their
42
43 infants are in hospital^{8 14 15 16} and their infants' complex needs after discharge.¹⁷
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51 Mothers of infants in neonatal intensive care face emotional challenges as they seek to find
52
53 a role for themselves in medically complex environments with perilously ill infants.¹⁸
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55 Wilkinson¹⁹ and others have explored the contentious ethical issues facing those who care
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3 for critically ill infants and the extent to which parents should be involved in decision-
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5 making. Little is known about the relationship between quality of mother-child interaction
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7 and child development after major neonatal surgery or intensive care, but the parental
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9 mental health and familial environment are thought to be vital to the recovery and mental
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11 well-being of the infant.²⁰⁻²²
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14 **Theoretical framework**

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16 One approach to thinking about these experiences could be to draw on the writings of the
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18 French sociologist Pierre Bourdieu whose work focused on examining experiences of social
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20 class and the production of knowledge and power^{23 24}. One of his key concepts was the
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22 notion of 'habitus', whereby individuals share their history and environment with others
23
24 who have similar positions, producing a 'stylistic affinity' and where 'social identity is
25
26 defined and asserted through difference'. Habitus is the way one unconsciously acts,
27
28 interacts and behaves within the social world in a 'taken for granted' manner, according to
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30 socialised norms, traditions and unwritten rules of particular groups²⁵. Bourdieu identifies
31
32 various forms of 'capital', economic, social and cultural resources that establish social
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34 standing within a particular habitus or social setting. Power is derived from configurations of
35
36 these types of capital²⁶ within a given field (in this case neonatal care and surgery) and.
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38 Although his writings focused on class lifestyles and social identity, these ideas could have
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40 resonance in interpreting the experiences of parents as they enter the world of highly-
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42 technical neonatal medicine and surgery and the knowledge of the professionals who work
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44 in these environments²⁷.
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3 The aim of this qualitative study was to: explore parents' experiences and perspectives of
4 having a baby who needs early surgery; identify the questions and problems that matter to
5 parents during and after their pregnancy and infant's surgery; and identify the long-term
6 impact on parents and families. In this article, we report on the period immediately before
7 and after surgery, and suggest actions that can be implemented to rapidly improve parent
8 experience. Findings on the longer-term impacts of these experiences will be reported
9 elsewhere.
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21 METHODS

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23 We conducted interviews with 44 parents, all of whom had an infant who needed surgery in
24 the first year of life. Two parents did not return their copyright form so their data is not
25 included in our analysis.
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33 Participants

34 Parents were recruited from England, Scotland and Wales. We interviewed parents whose
35 infant had required surgery in their first year of life. But we sought parents whose infant or
36 child was now a wide variety of differing ages, as we were keen to capture a long term, not
37 only a recent, perspective on the experiences. Therefore participants included those for
38 whom the experience was very recent through to parents whose son was 25 years old. Most
39 parents' infants were still living, but we interviewed the parents of one boy who died aged
40 seven months. We interviewed some mothers individually and eleven couples (mother and
41 father). Conditions that their infants had been diagnosed with included exomphalos,
42 gastroschisis, congenital diaphragmatic hernia, Hirschsprung's disease, inguinal hernia,
43 atresia (jejunal and oesophageal) and necrotising enterocolitis (see Table 1). Some
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3 conditions were diagnosed antenatally, others developed after their baby was born. Some
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5 conditions were congenital, others developed as a result of premature birth or
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7 spontaneously (see Table 1). All infants had their surgery in the first year of life, although
8
9 some went on to have multiple operations. Several spent extended periods of time in
10
11 neonatal intensive care units (see Table 1).
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14 15 16 Interviews

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18 Parents were interviewed either individually or in pairs, depending on preference. We
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20 interviewed eleven fathers, but none chose to be interviewed on their own. Recruitment
21
22 was through support groups, paediatric surgeons, neonatal nurses, other specialists and
23
24 word of mouth. We aimed for a maximum variation sample and continued interviews until
25
26 thematic saturation was reached. All interviews were conducted by LH, a social scientist, in
27
28 participants' own homes, or in a venue of their choice using a semi-structured narrative
29
30 approach²⁸. Interviewees were asked an open-ended question at the start of the interview,
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32 followed up by a semi-structured section to capture themes of particular interest. The
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34 interview schedule was developed by co-authors in consultation with the study advisory
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36 panel and a group of parent advisors. All interviews were audio recorded, and where
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38 consent was given video recorded to facilitate dissemination on the patient experience
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40 website, healthtalk.org. Parents were offered a two-stage consent and copyright approval
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42 process. They signed a consent form before the interview started and were subsequently
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44 sent a copy of their transcript to approve before signing a copyright form agreeing to their
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46 data being included in the analysis and excerpts from their interviews included in
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48 dissemination, including peer review articles, education materials and on the healthtalk.org
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50 website. Those who wanted to remain anonymous could choose to have only audio or
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3 written-only excerpts of their interviews included, and a pseudonym. Interviews lasted from
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5 between 75 minutes and 3 and a half hours. All interviews were fully transcribed. We
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7 undertook analysis of the transcribed interviews using an interpretive approach to thematic
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9 analysis.^{29 30} Interview transcripts, not videos, were coded by LH with support from NVIVO
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11 analysis software, using a framework which was developed iteratively and reflected both
12
13 anticipated and emergent themes. Coding reports were then analysed separately by LH and
14
15 LL using a modified grounded theory approach, incorporating constant comparison and
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17 exploration of deviant cases, allowing the data to be grouped into themes and all cases to
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19 be examined to ensure all the manifestations of each theme were accounted for and
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21 compared³¹ and we were satisfied we had reached data saturation with no new constructs
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23 emerging.³⁰ Any differences in interpretation were then discussed. MK and AML reviewed
24
25 summarised findings and contributed a further clinical layer of analysis
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33 **Ethics Committee Approval:** Ethics committee approval was given for this study by the
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35 Berkshire Ethics Committee, 09/H0505/66. All participants gave informed consent before
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37 taking part and have given written consent to their interview data being included in
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39 publications.
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44 RESULTS

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46 Some parents discovered there was a problem with their baby during antenatal scans,
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48 others not until after their baby had been born. Regardless of when the diagnosis came,
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50 parents of a baby who needs surgery faced many challenges over the ensuing months and
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52 years.
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3 The care pathways for these infants were often long and complex. Setbacks were common,
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5 and at no point could clinical staff give parents any guarantees. The practical and emotional
6
7 uncertainties were, therefore, huge. Living with uncertainty and worry was something
8
9 parents had to get used to, at every stage. Many parents described a lasting distress and
10
11 anxiety.
12
13

14
15
16 *“It was always a waiting game and tricky because you want to know the answer, ‘When is*
17
18 *my baby going to come home?’” (ID02, daughter with gastroschisis)*

19
20
21 *“We just don’t know what road he is going to take.” (ID20, mother, son with Hirschsprung’s*
22
23 *disease)*

24
25
26 *“My anxiety levels have been awful really it’s been hard for everybody because I’ve been up*
27
28 *and down emotionally”. (ID23, son with NEC)*
29

30
31
32 Large and complex teams of staff across many different specialities were involved in looking
33
34 after these infants over weeks, months and years. Our interviews highlighted some key
35
36 steps that could improve the experience for parents. These do not so much focus on the
37
38 surgery itself, but on the care and support parents are given before and after.
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- 42
43
44 i) Communication
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46 ii) Managing information and information overload
47
48 iii) Encouraging parents to seek out others (online, hospital groups)
49
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51 iv) Help in finding a role
52
53 v) Preparing for going home
54
55 vi) Open access policy
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57

Communication

Communication with the various health professionals looking after their baby was central to parents' experiences. These professionals spanned many disciplines – neonatologists, surgeons, but also paediatricians, intensive care nurses, specialist stoma nurses and other allied health professionals further along, such as physiotherapists or nutritionists.

The babies were often very sick with a rare condition and receiving complex medical and surgical treatments. Parents often felt isolated and struggled to find information about their baby's condition. Communication about how their baby's progress and the treatment plan was therefore very important.

"If you're in the dark that's when people would worry [...] as long as you, you know, either good or bad, what was going on and a lot of the things you ask them they don't know the answer because it's a time will tell kind of answer, but so long as someone tells you the time will tell sort of answer you've got an answer." (ID25, daughter with jejunal atresia)

There were often extended periods of uncertainty as doctors were not able to answer parents' questions. While these periods were a challenge to parents, there were examples of good, clear communication which really helped at a stressful, frightening time.

i) Being kept up to date

Being kept up to date with their baby's care was important to parents, especially when plans changed. They valued the opportunity to ask questions repeatedly. ID25 said she was

1
2
3 constantly asking questions but staff were very good at answering them all and reassuring
4
5 her.

6
7 *"[I] probably annoyed the hell out of them, but wanted to know, OK, when he does this what*
8 *is his next step, what has progressed to, how long will he be doing that and how long will it*
9 *take and things."* (ID15, son with CDH)

10
11
12
13 *The nurses were good as well at feeding back what the doctors had said and also if you had*
14 *any questions I felt comfortable saying look can you ask about this and let me know what*
15 *they say, so.* (ID30, son with gastroschisis)

16
17
18
19 ii) Communicating well

20
21 Although health professionals often had to deliver bad news, there were many examples of
22
23 good practice in managing this well. These interactions were characterised by giving parents
24
25 information in a clear, accessible manner, sometimes supported by drawing diagrams, but
26
27 without patronising/'dumbing down'. Parents appreciated doctors and nurses taking time
28
29 to answer their questions, not making them feel that any question was a silly one.

30
31
32
33 *M: And went through them with the consultant and actually again that was another thing*
34 *that he very patiently sat and went through every single one of those questions, however*
35 *stupid they were, you know.*

36
37 *F: How many times he'd heard them, no doubt.*

38
39 *M: Yeah and it didn't.*

40
41
42 *F: He wasn't fazed, he wasn't awkward he was just 'Okay, let's do it'.*
43 *(ID 43/44, mother and father, son with Hirschsprung's disease)*

44
45
46 *"I quite like things in a lot of detail so that when doctors are talking to you sometimes they*
47 *can do stupid talk because they don't know how much you know medically, but I like to hear*
48 *all of it and I don't want broken down terms, I want medical terms because then I can go and*
49 *look up what the medical terms are, see what it's all about."* (ID25, daughter with jejunal
50 atresia)

iii) Conveying expertise

When infants were in hospital for long periods, relationships of mutual respect between parents and healthcare professionals were hugely valued. As one mother explained, “you are handing over the most precious thing to this person who is going to put them under anaesthetic and disappear into an operating theatre with them and you hope their gonna come out the other side. So you have to have that level of assurance.” She and her husband were reassured by their surgeon’s “confidence not arrogance”. Others talked about the importance of trust and feeling as though their baby was in expert hands, cared for by clinicians who were knowledgeable about their condition.

“They’ve got this under control, they really know what they are doing..... In a way it’s silly thinking that now because of course they know what they’re doing these are highly trained professionals but in that moment that’s what you want to hear cos you just want to, you’re handing over your child so you want someone to be right on it don’t you and he was.” (ID26, father, daughter with inguinal hernia)

iv) Being listened to and feeling part of the team

While parents recognised that they relied on doctors’ expertise and judgement in planning their baby’s care, they really valued feeling involved in their baby’s care – “part of it, part of that team”.

“They’ve been very understanding and patient and I think recognising as well our role as parents and, that we, you know, have opinions and experiences, and not devaluing what we’ve learnt from other places as well.” (ID01, son with exomphalos)

“I would say 99.9% of the time we’ve been treated really well, like human beings, not just numbers, and that has made an enormous difference to the experience as a family.” (ID03, daughter with exomphalos)

But parents’ communication did not always go so well and parents could find this very undermining, particularly at such a stressful and worrying time. One parent (ID37) felt that

1
2
3 the doctors looking after her daughter didn't respect her wish to breastfeed, and had an
4
5 attitude that parents were part of the problem rather than part of the solution, which
6
7 frustrated her.
8

9
10 Unlike parent ID01, one mother (ID19) felt that doctors were very dismissive of the research
11
12 and expert patient knowledge she had gathered from online support groups.
13

14 *So yeah the surgeons need to learn how to not go 'Oh the internet' every time you suggest*
15 *that someone has [laughs] mentioned this to you [laughs] because it's not just Googling*
16 *symptoms and getting an answer it's asking a forum of parents who've been through exactly*
17 *what you're going through. It's like sitting in a room with 500 parents whose kids have got*
18 *the same experience and had the same problem who'll all have widely different experiences*
19 *of it and the surgeon just going 'I'm not listening to any of you lot,' what surgeon would*
20 *stand in a room of parents and do that but because it's on the internet it seems to be*
21 *acceptable to go 'Tut, Facebook.'* (ID19, daughter with exomphalos)
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26 **Managing information and information overload**

27
28 Understanding the diagnosis and possible journey ahead can be overwhelming for parents.

29
30 Parents often felt powerless, both during pregnancy and once their baby had been born.

31
32 Information – about the condition and procedures but also other parent experiences – was
33
34 crucial in helping parents come to terms with the diagnosis. Seeking out information played
35
36 a central role, helping parents feel they were actively doing something for their baby and
37
38 family. ID01's son had exomphalos. Seeking information felt like the only thing she and her
39
40 husband could do. *"We were powerless to change anything other than lots of information".*
41
42
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44

45
46 However, there were also dangers of information overload. Parents could find it hard to
47
48 take on board a great deal of complex information at once, and needed time to understand
49
50 and process what was happening to their baby. Parent ID22's son was diagnosed with
51
52 Hirschsprung's disease. She was given an information sheet and some medical alert cards so
53
54 they could identify any symptoms of things going wrong.
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1
2
3 *“They gave us enough information but not too much because I think they obviously realised*
4 *that, you know, it’s early days but they had to highlight the seriousness of it and that, know*
5 *if anything if he was showing any signs of anything you’re to bring him back basically.”*
6 (ID22)
7

8
9
10 On the whole, parents said the information given by hospitals was not sufficient and they
11 supplemented it with their own background reading and research. Pointing parents in the
12 direction of trusted sources of information would be a key easy action to help them.
13
14

15 16 17 18 19 **Encouraging parents to seek out others**

20
21 Finding support from other parents who had been through similar experiences (either
22 online or face to face) was described as a crucial factor in helping parents cope and
23 understand more about their baby’s diagnosis.
24
25

26
27
28 *“Find parents, my absolute number one thing.”* (ID01, son with exomphalos)
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30
31 *“That was my number one support during that time with all these other mums who’d gone*
32 *through it.”* (ID02, daughter with gastroschisis).
33

34
35 Staff can encourage and facilitate this through introducing parents to each other, or
36 suggesting online support groups. One unit had established a popular and thriving Facebook
37 support group for parents of babies with Hirschsprung’s disease.
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42 *“It just makes it a bit real, you know, that you aren’t the only one”.* (ID22, son with
43 Hirschsprung’s disease)
44

45 46 47 48 49 **Helping parents find a role**

50
51 Parents often described how “useless” or “helpless” they felt not being able to do anything
52 for their baby while in hospital. Yet when they went home they were going to become
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2
3 experts in their baby's care. Helping them bridge this gap was an area where staff could
4
5 make a real impact.
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9 *"I think you're so wrapped up in the medical needs of your baby and hoping that they're*
10 *going to be alive at the end of it that I just...hadn't anticipated that the little things would be*
11 *the things that matter, it would be the 'mummy' things that had been so easy to do with my*
12 *other children, they would be the things that would matter that I missed out on."* (ID19,
13 daughter with exomphalos).
14

15
16 In the early days, spending time at their baby's side was all many parents felt they could do.
17

18 They looked for small ways they could regain a sense of control and get involved in their
19 baby's care. While it was not always practical in critical care environments, parents
20 appreciated helping with feeding, bathing, singing and talking to their baby where possible.
21

22 After three weeks, ID02 was able to hold her daughter for the first time, *"it was like*
23 *Christmas"*. Supporting mothers to either breastfeed or, more often, express milk for their
24 baby, was another way of parents bonding and being involved in their baby's care. Some
25 parents described how they were supported and encouraged to become "experts" in
26 aspects of their baby's daily care – changing dressings or stoma bags. One father (ID05) said
27 he became the "dressing king"; after a rocky start. Another (ID03) became an expert at
28 dressing her daughter's exomphalos, *"treating and dressing it was still a bit of a skill. It got*
29 *easier and easier and it's a real shame. I'm now one of the finest exomphalos wrappers in*
30 *[county] and it's not a skill that's really going to be used that much, is it?"*
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46 Activities like these were key to bridging the gap between hospital and home.
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51 **Preparing to go home**

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53 After weeks or months in hospital, being able to bring their baby home was a huge step for
54 many parents. While a positive sign that their baby was on the mend, it could also be
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1
2
3 daunting to leave the “safety net” of hospital and clinical expertise. Some parents described
4
5 handover or normalisation programmes as very helpful in preparing them technically and
6
7 emotionally for caring for their infant at home. Parents were trained in some of the skills
8
9 they would need (wound management, stoma care, first aid, resuscitation) and given the
10
11 opportunity to ‘room in’ with their baby for a few nights before going home.
12
13

14 *“You’re totally encouraged to do as much care for your baby as you can. It’s your baby,*
15 *they’re there to support you and to medically [um] jump in if, if need be, but don’t expect*
16 *that they’re there to feed and care for your baby because that’s your job.”* (ID34, son with
17 *gastroschisis)*
18
19

20 21 **Open access policy**

22
23 Accessing hospitals and specialists after their baby had been sent home could be challenging
24
25 for parents, especially if home was a distance from the specialist surgical centre. When
26
27 problems came up, as they often did, it was hard to know where to take their baby. So being
28
29 given open or emergency access back to the team who had looked after their baby, without
30
31 having to go through A&E first, was really valued by parents. ID38’s son had complex needs
32
33 after his surgery for oesophageal atresia and trachea-oesophageal fistula (TOF) said having
34
35 open access to the ward where they can turn up with their baby and see doctors who know
36
37 their baby was so important. *“I know that won’t last forever but right now the open access is*
38
39 *a Godsend because it means we get seen really quickly.”*
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47 **DISCUSSION**

48
49 This study adds valuable insights into the support and information needs of parents when
50
51 their baby requires early surgery. These surgical journeys are often a long haul for baby and
52
53 parents. Our study highlights the importance of clear and ongoing communication between
54
55 parents and the often large, multi-disciplinary teams caring for their infant and points to
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2
3 immediate actions that can improve parent experiences and outcomes. Parents value being
4
5 listened to, encouraged to be a part of the care team and supported in finding a role for
6
7 themselves. They need information from the professionals caring for their infant but also
8
9 recommendations of good sources of information to supplement their knowledge, while
10
11 being mindful of information overload. For some, encouraging them to seek support from
12
13 other parents is of great value.
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17
18 Previous work exploring parents' experiences of having an infant in NICU or surgery has
19
20 highlighted the importance of good communication and emotional support, giving parents
21
22 support at handover for surgery and pointed to the impact of scanty and infrequent
23
24 information giving.^{7 32} Parents experiences are not only affected by their baby's diagnosis
25
26 and care, but also the ways in which services are organised to support families to navigate
27
28 the systems and maintain a new 'second campus' as they look after their baby and continue
29
30 their lives outside the hospital.³³
31
32

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34
35 Involving and supporting parents is increasingly recognised as an important component of
36
37 providing holistic paediatric care and can help with the uncertainty of parenting an infant
38
39 during critical illness. Parent experiences of NICU point to the vital role that neonatal nurses
40
41 have in engaging with mothers and the importance of that relationship.³³ Aagaard⁵
42
43 discussed the importance of trying to strengthen maternal competence, and suggested
44
45 parent-nurse chat as a communication strategy. Our findings provide examples of the ways
46
47 in which encouraging parents to be involved with infant can be achieved.
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3 Others have described the role of the expert parent³³ and home monitoring programmes
4 after cardiac surgery.^{17 34} Studies have indicated that parents are not adequately prepared
5 for discharge and are not well equipped to recognise deterioration in their child. The
6
7 positive examples of being prepared for discharge and supported in becoming the primary
8
9 carer offer insights into how parents might be supported to manage this transition.
10
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15
16 Bourdieu's theoretical concepts of habitus and capital are helpful in exploring and
17
18 unpacking the experiences of parents in these highly technical environments and the value
19
20 they place on communication, finding their own role and seeking out other parents. They
21
22 travel a journey from being newcomers in an environment (neonatal/surgical unit) where
23
24 they are unfamiliar with the socialised norms. They have little capital and no idea how to
25
26 'play the game' (what Bourdieu termed the logic of practice) and negotiate the field. There
27
28 is initially an unequal balance of power. Thus examples of parents feeling dismissed (or part
29
30 of the problem) amplify this imbalance. Feeling included in the team caring for their infant
31
32 and having their expertise (in changing dressings, feeding etc) supported and celebrated can
33
34 be a powerful tool in addressing this imbalance . Over time, assisted by good
35
36 communication from the health professionals and the networks of support and information
37
38 provided by other parents, parents develop confidence and competency which Bourdieu
39
40 might have interpreted as social and cultural capital. Their social capital is extended through
41
42 the social networks they develop inside and outside the hospital environment, online and in
43
44 the real world, related to their new role in caring for their infant. Their cultural capital is
45
46 extended through the knowledge, expertise and skills they develop to care for their infant.
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49 By the time they take their infants home these parents are well on the way to becoming
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60 technical experts in their baby's illness and care.

STRENGTHS AND LIMITATIONS

This is a UK based study that sought to explore the experiences of parents who have an infant requiring surgery in the first year of life. Interview studies in this field are rare and our study provides rich insights into the emotional and practical impacts of these experiences. While the interviews could not cover all possible conditions, they provide insights that may be generalisable across many different surgical procedures/medical conditions. However, there are several limitations worth considering. We interviewed parents at different lengths of time after their surgery, as we sought to gain insights into the long term as well as short term impacts of these experiences. However this variation could have influenced parents' recall of events. Parents were asked to describe an intense and often protracted period of their lives in one interview, so it is perhaps inevitable that some details were omitted or compressed. There was also a variety in interviews, with some parents choosing to be interviewed alone, and others in couples. This inevitably means that some interviews are co-produced while others are not.

CONCLUSION

As babies recover, the potential for parental expertise grows. Our study highlights the vital role of information, both about the condition and about the infant's progress. Health care staff could discuss or direct parents to information sources, seek to empower parents through involving them with their infant's care where possible, and link them with other parents.

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3 **A Contributorship statement** The study was conceived by MK. All interviews were collected by
4 LH. Analysis was undertaken by LH and LL, with input from MK and AM. LH wrote the article, with
5 input from the other authors.
6

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8

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14
15

16 **D Data Sharing statement** Participants were invited to review their transcript and mark any
17 sections that they did not want used before transferring copyright to the University of Oxford for use
18 in research, teaching, publications and broadcasting. These carefully anonymised transcripts form
19 part of a University of Oxford archive which is available to other bona fide research teams for
20 secondary analysis. All authors had access to the all of the data in the study and take responsibility
21 for the integrity of the data and the accuracy of the data analysis.
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Table of Participants

Table 1 Participants					
Condition	Identifier	Parent Mother/Father	Sex of child	Child's age at interview	Intensive or high dependency care admission
Exomphalos*	01	M	m	18 months	Yes
	02	M	f	6 years	Yes
	03	M	f	8 years	Yes
	04/05	M&F	f	8 years	Yes
	12/13	M&F	m	25 years	No
	16/17	M&F	m	13 years	Yes
	19	M	f	16 months	Yes
	41/42	M&F	m	Died age 7 months	Yes
Necrotising Enterocolitis	08	M	m	9 months	Yes
	09	M	m	11 months	Yes
	23	M	m	6 months	Yes
Hernia	26/27	M&F	f	9 months	No
Congenital Diaphragmatic Hernia*	10/11	M&F	m	9 months	Yes
	15	M	m	5 years	Yes
	24	M	m	9 years	Yes
Hirschprung's Disease*	18	M	f	1 year	No
	20/21	M&F	m	4 months	Yes
	22	M	m	16 months	No
	28/29	M&F	m	19 months	No
	39/40	M&F	m	5 years old	No
	43/44	M&F	m	5 years old	No
Gastroschisis*	30	M	m	7 ½ months	Yes
	31	M	m	4 years	Yes
	32	M	f	3 years	Yes
	33/34	M&F	m	3 months	Yes
	36	M	f	19 months	Yes
	37	M	f	6 years	Yes
Short Bowel	35	M	f	7 years	Yes
Jejunal atresia*	25	M	f	4 months	Yes

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Oesophageal Atresia with trachea-oesophageal fistula*	38		m	19 months	Yes
Undiagnosed	14		m	6 months	
*Congenital diagnosis					

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COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	p.8
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	p.1 & 8
Occupation	3	What was their occupation at the time of the study?	p.1
Gender	4	Was the researcher male or female?	p.1
Experience and training	5	What experience or training did the researcher have?	p.1
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	NO
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	p.8
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	p.8
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	p.6 & 9
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	p.8
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	p.8
Sample size	12	How many participants were in the study?	p.7
Non-participation	13	How many people refused to participate or dropped out? Reasons?	p.7
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	p.8
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	No
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	Table 1
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	No, but can be
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	No
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	p.8
Field notes	20	Were field notes made during and/or after the interview or focus group?	Yes
Duration	21	What was the duration of the interviews or focus group?	p.9
Data saturation	22	Was data saturation discussed?	p.9
Transcripts returned	23	Were transcripts returned to participants for comment and/or	p.8

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	p.9
Description of the coding tree	25	Did authors provide a description of the coding tree?	No
Derivation of themes	26	Were themes identified in advance or derived from the data?	p.9
Software	27	What software, if applicable, was used to manage the data?	p.9
Participant checking	28	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	P.10-17
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Yes
Clarity of major themes	31	Were major themes clearly presented in the findings?	Yes
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Yes

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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BMJ Open

What can make things better for parents when babies need abdominal surgery in their first year of life? A qualitative interview study in the United Kingdom

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8 What can make things better for parents when babies need
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11 abdominal surgery in their first year of life? A qualitative
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14 interview study in the United Kingdom
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ABSTRACT

(i) Objectives

To understand the experiences of parents of infants who required surgery early in life. To identify messages and training needs for the extended clinical teams caring for these families – including paediatric surgeons, neonatologists, nurses, obstetricians, midwives and sonographers.

(ii) Setting

United Kingdom wide interview study, including England, Wales and Scotland.

(iii) Participants

In-depth interviews were conducted with 44 parents who had a baby who underwent early abdominal surgery. Conditions included those diagnosed antenatally (e.g. exomphalos, gastroschisis, congenital diaphragmatic hernia) or which were detected postnatally (e.g. Hirschsprung's disease, necrotising enterocolitis). Interviews were video and audio recorded and analysed using a modified grounded-theory approach.

(iv) Results

While some parents reported experiencing excellent communication and felt they were listened to and involved by the care team, this was not always the case.

Dealing with large, complex medical and surgical teams could result in conflicting messages, uncertainty and distress. Parents wanted information but also described being overwhelmed and wanting to distance themselves to maintain hope.

Information and support from other parents in hospital and online groups was highly valued. Of particular concern was support when going home and caring for their baby after discharge; an open access policy for readmission offered a helpful safety net.

(v) Conclusions

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3 Listening to the experience of parents provides rich data to enhance clinical
4 understandings on how to improve information and communication with parents, and
5 ameliorate the deep and lasting distress and anxiety that some parents feel when
6 their infants face early surgery. We suggest that the writings of Bourdieu could have
7 resonance in interpreting the experiences of parents as they enter the world of
8 highly-technical neonatal medicine and surgery and the knowledge of the
9 professionals who work in these environments.
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18 Article Summary

19 Strengths and Limitations

- 20 • This is a UK based study that sought to explore the experiences of parents
21 who have an infant requiring abdominal surgery in the first year of life.
- 22 • Interview studies in this field are rare and our study provides rich insights into
23 the emotional and practical impacts of these experiences.
- 24 • While the interviews could not cover all possible conditions, they provide
25 insights that may be generalisable across many different surgical
26 procedures/medical conditions.
- 27 • Interviews were conducted at varying distances from the event, so recall was
28 varied. Parents described an intense and often protracted period of their lives,
29 so some details may have been omitted or compressed in their accounts.
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47 INTRODUCTION

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49 The experiences of parents of infants who undergo abdominal surgery in the first
50 year of life are rarely recorded. Even after discharge from hospital, these infants may
51 require multiple outpatient visits to different specialist clinics and their ongoing care
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3 requirements can have significant effects on the quality of life of parents and existing
4 children, as well as economic effects through lost work days.
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9 Many of these infants will require surgery because of a gastrointestinal congenital
10 anomaly, such as exomphalos, gastroschisis or Hirschsprung's disease. These
11 conditions are under-researched¹, understanding of them is poor and interventions
12 are rarely based on robust evidence. Routine sources of information are limited.²
13 Outcomes for infants with rare anomalies are improving^{3 4} and so the need for
14 rigorous research into surgical, clinical and long-term outcomes is paramount.²
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16 Alongside this, understanding the impact of these diagnoses and surgical treatments
17 on parents and families is central to their long-term recovery.
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28 This study was conducted as an adjunct to the British Association of Paediatric
29 Surgeons Congenital Anomaly Surveillance System (BAPS-CASS) and was focused
30 on parents' experiences of abdominal surgery. There is little research on parent
31 experiences of conditions that require early abdominal surgery. However, we can
32 supplement this limited evidence base by drawing on research into parent
33 experiences of congenital heart disease and surgery and more generally research
34 about parents' experiences of neonatal intensive care units. The literature here
35 points to the practical and psychological impact on families^{5 6} and the importance of
36 good communication between parents and staff.⁷ Parents of children with congenital
37 heart disease are at high risk for mental health morbidity, experiencing stress,
38 depression, anxiety and traumatic stress responses⁸⁻¹² and the cost implications are
39 profound.¹³ Parents experience difficulties with bonding and breastfeeding while their
40 infants are in hospital^{8 14 15 16} and their infants' complex needs after discharge.¹⁷
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5 Mothers of infants in neonatal intensive care face emotional challenges as they seek
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7 to find a role for themselves in medically complex environments with perilously ill
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9 infants.¹⁸ Wilkinson¹⁹ and others have explored the contentious ethical issues facing
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11 those who care for critically ill infants and the extent to which parents should be
12
13 involved in decision-making. Little is known about the relationship between quality of
14
15 mother-child interaction and child development after major neonatal surgery or
16
17 intensive care, but the parental mental health and familial environment are thought to
18
19 be vital to the recovery and mental well-being of the infant.²⁰⁻²²
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23 **Theoretical framework**

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25 One approach to thinking about these experiences could be to draw on the writings
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27 of the French sociologist Pierre Bourdieu whose work focused on examining
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29 experiences of social class and the production of knowledge and power^{23 24}. One of
30
31 his key concepts was the notion of 'habitus', whereby individuals share their history
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33 and environment with others who have similar positions, producing a 'stylistic affinity'
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35 and where 'social identity is defined and asserted through difference'. Habitus is the
36
37 way one unconsciously acts, interacts and behaves within the social world in a 'taken
38
39 for granted' manner, according to socialised norms, traditions and unwritten rules of
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41 particular groups²⁵. Bourdieu identifies various forms of 'capital', economic, social
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43 and cultural resources that establish social standing within a particular habitus or
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45 social setting. Power is derived from configurations of these types of capital²⁶ within
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47 a given field (in this case neonatal care and surgery). Although his writings focused
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49 on class lifestyles and social identity, these ideas could have resonance in
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51 interpreting the experiences of parents as they enter the world of highly-technical
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3 neonatal medicine and surgery and the knowledge of the professionals who work in
4 these environments²⁷.
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9 The aim of this qualitative study was to: explore parents' experiences and
10 perspectives of having a baby who needs early abdominal surgery; identify the
11 questions and problems that matter to parents during and after their pregnancy and
12 infant's surgery; and identify the long-term impact on parents and families. In this
13 article, we report on the period immediately before and after surgery, and suggest
14 actions that can be implemented to rapidly improve parents' experiences. Findings
15 on the longer-term impacts of these experiences will be reported elsewhere.
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26 METHODS

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29 We conducted interviews with 44 parents, all of whom had an infant who needed
30 abdominal surgery in the first year of life. Two parents did not return their copyright
31 form so their data is not included in our analysis.
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38 Participants

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40 Parents were recruited from England, Scotland and Wales. We interviewed parents
41 whose infant had required surgery in their first year of life. We were keen to capture
42 long term perspectives on the experiences, as well as recent ones. So we sought
43 parents whose infant or child was now a wide variety of differing ages. Therefore
44 participants included those for whom the experience was very recent through to
45 parents whose son was 25 years old. Most parents' infants were still living, but we
46 interviewed the parents of one boy who died aged seven months. We interviewed
47 some mothers individually and eleven couples (mother and father). Conditions that
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3 their infants had been diagnosed with included exomphalos, gastroschisis,
4 congenital diaphragmatic hernia, Hirschsprung's disease, inguinal hernia, atresia
5 (jejunal and oesophageal) and necrotising enterocolitis (see Table 1). Some
6 conditions were diagnosed antenatally, others developed after their baby was born.
7 Some conditions were congenital, others developed as a result of premature birth or
8 spontaneously (see Table 1). All infants had their surgery in the first year of life,
9 although some went on to have multiple operations. Several spent extended periods
10 of time in neonatal intensive care units (see Table 1).
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22 Interviews

23 Parents were interviewed either individually or in pairs, depending on preference. We
24 interviewed eleven fathers, but none chose to be interviewed on their own.
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28 Recruitment was through support groups, paediatric surgeons, neonatal nurses,
29 other specialists and word of mouth. We aimed for a maximum variation sample and
30 continued interviews until thematic saturation was reached. All interviews were
31 conducted by LH, a social scientist, in participants' own homes, or in a venue of their
32 choice using a semi-structured narrative approach²⁸. The interviews were in two
33 parts, beginning with an invitation to offer an unstructured narrative, prompted by an
34 open-ended question at the start of the interview. This was followed up by a semi-
35 structured component of the interview with prompts to follow up issues raised in the
36 narrative and to explore themes suggested by the literature and the advisory panel
37 and a group of parent advisors. The interview schedule was developed by co-
38 authors in consultation with the study advisory panel and parent advisors. All
39 interviews were audio recorded, and where consent was given video recorded to
40 facilitate dissemination on the patient experience website, healthtalk.org. Parents
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3 were offered a two-stage consent and copyright approval process. They signed a
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5 consent form before the interview started and were subsequently sent a copy of their
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7 transcript to approve before signing a copyright form agreeing to their data being
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9 included in the analysis and excerpts from their interviews included in dissemination,
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11 including peer review articles, education materials and on the healthtalk.org website.
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13 Those who wanted to remain anonymous could choose to have only audio or written-
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15 only excerpts of their interviews included, and a pseudonym. Interviews lasted from
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17 between 75 minutes and 3 and a half hours. All interviews were fully transcribed. We
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19 undertook analysis of the transcribed interviews using an interpretive approach to
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21 thematic analysis^{29 30}. Interview transcripts, not videos, were coded by LH with
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23 support from NVIVO analysis software, using a framework which was developed
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25 iteratively and reflected both anticipated and emergent themes. Coding reports were
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27 then analysed separately by LH and LL using a modified grounded theory approach,
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29 incorporating constant comparison and exploration of deviant cases, allowing the
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31 data to be grouped into themes and all cases to be examined to ensure all the
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33 manifestations of each theme were accounted for and compared³¹ and we were
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35 satisfied we had reached data saturation with no new constructs emerging³⁰. Any
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37 differences in interpretation were then discussed. MK and AML reviewed
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39 summarised findings and contributed a further clinical layer of analysis.
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42 Patient and Public Involvement

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44 A parent advisory panel was established at the inception of the study and met
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46 annually. Parents with lived experiences of having an infant who required neonatal
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48 surgery were involved in the face to face meetings or via email. Parents contributed
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50 to the design of the sample and interview schedule, helped with recruitment and
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3 provided feedback on initial analysis and the final documents published on the
4 Healthtalk.org website. Parents were invited to a launch event for the website.
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9 **Ethics Committee Approval:** Ethics committee approval was given for this study by
10 the Berkshire Ethics Committee, 09/H0505/66. All participants gave informed
11 consent before taking part and have given written consent to their interview data
12 being included in publications.
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20 RESULTS

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22 Some parents discovered there was a problem with their baby during antenatal
23 scans, others not until after their baby had been born. Regardless of when the
24 diagnosis came, parents of a baby who needs abdominal surgery faced many
25 challenges over the ensuing months and years.
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33 The care pathways for these infants were often long and complex. Setbacks were
34 common, and at no point could clinical staff give parents any guarantees. The
35 practical and emotional uncertainties were, therefore, huge. Living with uncertainty
36 and worry was something parents had to get used to, at every stage. Many parents
37 described a lasting distress and anxiety.
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46 *"It was always a waiting game and tricky because you want to know the answer,*

47 *'When is my baby going to come home?'" (ID02, mother, daughter with*
48 *gastroschisis)*
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52 *"We just don't know what road he is going to take." (ID20, mother, son with*
53 *Hirschsprung's disease)*
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3 *“My anxiety levels have been awful really it’s been hard for everybody because I’ve*
4 *been up and down emotionally”. (ID23, mother, son with NEC)*
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9 Large and complex teams of staff across many different specialities were involved in
10 looking after these infants over weeks, months and years. Our interviews highlighted
11 some key steps that could improve the experience for parents. These do not so
12 much focus on the surgery itself, but on the care and support parents are given
13 before and after.
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22 i) Communication
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24 ii) Managing information and information overload
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26 iii) Encouraging parents to seek out others (online, hospital groups)
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28 iv) Help in finding a role
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30 v) Preparing for going home
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32 vi) Open access policy
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40 **Communication**

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42 Communication with the various health professionals looking after their baby was
43 central to parents’ experiences. These professionals spanned many disciplines –
44 neonatologists, surgeons, but also paediatricians, intensive care nurses, specialist
45 stoma nurses and other allied health professionals further along, such as
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physiotherapists or nutritionists.

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3 The babies were often very sick with a rare condition and receiving complex medical
4 and surgical treatments. Parents often felt isolated and struggled to find information
5 about their baby's diagnosis and condition. Communication about their baby's
6 progress and the treatment plan was therefore very important.
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12 *"If you're in the dark that's when people would worry [...] as long as you, you know,
13 either good or bad, what was going on and a lot of the things you ask them they
14 don't know the answer because it's a time will tell kind of answer, but so long as
15 someone tells you the time will tell sort of answer you've got an answer."* (ID25,
16 mother, daughter with jejunal atresia)
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19
20 There were often extended periods of uncertainty as doctors were not able to answer
21 parents' questions. While these periods were a challenge to parents, there were
22 examples of good, clear communication which really helped at a stressful, frightening
23 time.
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31 i) Being kept up to date
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33 Being kept up to date with their baby's care was important to parents, especially
34 when plans changed. They valued the opportunity to ask questions repeatedly. ID25
35 said she was constantly asking questions but staff were very good at answering
36 them all and reassuring her.
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42 *"[I] probably annoyed the hell out of them, but wanted to know, OK, when he does
43 this what is his next step, what has progressed to, how long will he be doing that and
44 how long will it take and things."* (ID15, mother, son with CDH)
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47 *The nurses were good as well at feeding back what the doctors had said and also if
48 you had any questions I felt comfortable saying look can you ask about this and let
49 me know what they say, so.* (ID30, mother, son with gastroschisis)
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ii) Communicating well

Although health professionals often had to deliver bad news, there were many examples of good practice in managing this well. These interactions were characterised by giving parents information in a clear, accessible manner, sometimes supported by drawing diagrams, but without patronising or 'dumbing down'. Parents appreciated doctors and nurses taking time to answer their questions, not making them feel that any question was a silly one.

M: And went through them with the consultant and actually again that was another thing that he very patiently sat and went through every single one of those questions, however stupid they were, you know.

F: How many times he'd heard them, no doubt.

M: Yeah and it didn't.

*F: He wasn't fazed, he wasn't awkward he was just 'Okay, let's do it'.
(ID 43/44, mother and father, son with Hirschsprung's disease)*

"I quite like things in a lot of detail so that when doctors are talking to you sometimes they can do stupid talk because they don't know how much you know medically, but I like to hear all of it and I don't want broken down terms, I want medical terms because then I can go and look up what the medical terms are, see what it's all about." (ID25, mother, daughter with jejunal atresia)

iii) Conveying expertise

When infants were in hospital for long periods, relationships of mutual respect between parents and healthcare professionals were hugely valued. As one mother explained, "you are handing over the most precious thing to this person who is going to put them under anaesthetic and disappear into an operating theatre with them and you hope their gonna come out the other side. So you have to have that level of assurance." She and her husband were reassured by their surgeon's "confidence not arrogance". Others talked about the importance of trust and feeling as though their

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3 baby was in expert hands, cared for by clinicians who were knowledgeable about
4
5 their condition.

6
7 *“They’ve got this under control, they really know what they are doing…… In a way*
8 *it’s silly thinking that now because of course they know what they’re doing these are*
9 *highly trained professionals but in that moment that’s what you want to hear cos you*
10 *just want to, you’re handing over your child so you want someone to be right on it*
11 *don’t you and he was.”* (ID26, father, daughter with inguinal hernia)
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14 15 16 17 iv) Being listened to and feeling part of the team

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19 While parents recognised that they relied on doctors’ expertise and judgement in
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21 planning their baby’s care, they really valued feeling involved in caring for their baby
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23 where they could – “part of it, part of that team”.
24

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26 *“They’ve been very understanding and patient and I think recognising as well our*
27 *role as parents and, that we, you know, have opinions and experiences, and not*
28 *devaluing what we’ve learnt from other places as well.”* (ID01, mother, son with
29 exomphalos)
30

31 *“I would say 99.9% of the time we’ve been treated really well, like human beings, not*
32 *just numbers, and that has made an enormous difference to the experience as a*
33 *family.”* (ID03, mother, daughter with exomphalos)
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37 But communication did not always go so well and parents could find this very
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39 undermining, particularly at such a stressful and worrying time. One parent (ID37)
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41 felt that the doctors looking after her daughter didn’t respect her wish to breastfeed,
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43 and had an attitude that parents were part of the problem rather than part of the
44
45 solution, which frustrated her.

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47 Unlike parent ID01, one mother (ID19) felt that doctors were very dismissive of the
48
49 research and expert patient knowledge she had gathered from online support
50
51 groups.
52

53
54 *So yeah the surgeons need to learn how to not go ‘Oh the internet’ every time you*
55 *suggest that someone has [laughs] mentioned this to you [laughs] because it’s not*
56 *just Googling symptoms and getting an answer it’s asking a forum of parents who’ve*
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3 *been through exactly what you're going through. It's like sitting in a room with 500*
4 *parents whose kids have got the same experience and had the same problem who'll*
5 *all have widely different experiences of it and the surgeon just going 'I'm not listening*
6 *to any of you lot,' what surgeon would stand in a room of parents and do that but*
7 *because it's on the internet it seems to be acceptable to go 'Tut, Facebook.'* (ID19,
8 mother, daughter with exomphalos)
9

10 11 **Managing information and information overload**

12
13
14 Understanding the diagnosis and possible journey ahead can be overwhelming for
15
16 parents. Parents often felt powerless, both during pregnancy and once their baby
17
18 had been born. Information – about the condition and procedures but also other
19
20 parent experiences – was crucial in helping parents come to terms with the
21
22 diagnosis. Seeking out information played a central role, helping parents feel they
23
24 were actively doing something for their baby and family. ID01's son had exomphalos.
25
26 Seeking information felt like the only thing she and her husband could do. *"We were*
27 *powerless to change anything other than lots of information"*.
28
29

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31
32
33 However, there were also dangers of information overload. Parents could find it hard
34
35 to take on board a great deal of complex information at once, and needed time to
36
37 understand and process what was happening to their baby. ID22's son was
38
39 diagnosed with Hirschsprung's disease. She was given an information sheet and
40
41 some medical alert cards so they could identify any symptoms of things going wrong.
42
43
44 *"They gave us enough information but not too much because I think they obviously*
45 *realised that, you know, it's early days but they had to highlight the seriousness of it*
46 *and that, know if anything if he was showing any signs of anything you're to bring*
47 *him back basically."* (ID22, mother, son with Hirschsprung's disease)
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50
51 On the whole, parents said the information given by hospitals was not sufficient and
52
53 they supplemented it with their own background reading and research. Pointing
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3 parents in the direction of trusted sources of information would be a key easy action
4
5 to help them.
6
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8

9 10 **Encouraging parents to seek out others**

11 Finding support from other parents who had been through similar experiences (either
12
13 online or face to face) was described as a crucial factor in helping parents cope and
14
15 understand more about their baby's diagnosis.
16

17
18 *"Find parents, my absolute number one thing."* (ID01, mother, son with exomphalos)
19

20
21 *"That was my number one support during that time with all these other mums who'd*
22 *gone through it."* (ID02, mother, daughter with gastroschisis).
23

24
25 Staff can encourage and facilitate this through introducing parents to each other, or
26
27 suggesting online support groups. One unit had established a popular and thriving
28

29 Facebook support group for parents of babies with Hirschsprung's disease.
30

31
32 *"It just makes it a bit real, you know, that you aren't the only one".* (ID22, mother, son
33 with Hirschsprung's disease)
34

35 36 37 38 **Helping parents find a role**

39
40 Parents often described how "useless" or "helpless" they felt not being able to do
41
42 anything for their baby while in hospital. Yet when they went home they were going
43
44 to become experts in their baby's care. Helping them bridge this gap was an area
45
46 where staff could make a real impact.
47
48

49
50 *"I think you're so wrapped up in the medical needs of your baby and hoping that*
51 *they're going to be alive at the end of it that I just...hadn't anticipated that the little*
52 *things would be the things that matter, it would be the 'mummy' things that had been*
53 *so easy to do with my other children, they would be the things that would matter that*
54 *I missed out on."* (ID19, mother, daughter with exomphalos).
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1
2
3 In the early days, spending time at their baby's side was all many parents felt they
4 could do. They looked for small ways they could regain a sense of control and get
5 involved in their baby's care. While it was not always practical in critical care
6 environments, parents appreciated helping with feeding, bathing, singing and talking
7 to their baby where possible. After three weeks, ID02 was able to hold her daughter
8 for the first time, "*it was like Christmas*". Supporting mothers to either breastfeed or,
9 more often, express milk for their baby, was another way of parents bonding and
10 being involved in their baby's care. Some parents described how they were
11 supported and encouraged to become "experts" in aspects of their baby's daily care
12 – changing dressings or stoma bags. One father (ID05) said he became the
13 "dressing king"; after a rocky start. Another (ID03) became an expert at dressing her
14 daughter's exomphalos, "*treating and dressing it was still a bit of a skill. It got easier*
15 *and easier and it's a real shame. I'm now one of the finest exomphalos wrappers in*
16 *[county] and it's not a skill that's really going to be used that much, is it?"*
17
18 Activities like these were key to bridging the gap between hospital and home.
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38 **Preparing to go home**

39
40 After weeks or months in hospital, being able to bring their baby home was a huge
41 step for many parents. While a positive sign that their baby was on the mend, it could
42 also be daunting to leave the "safety net" of hospital and clinical expertise. Some
43 parents described handover or normalisation programmes as very helpful in
44 preparing them technically and emotionally for caring for their infant at home.
45
46 Parents were trained in some of the skills they would need (wound management,
47 stoma care, first aid, resuscitation) and given the opportunity to 'room in' with their
48 baby for a few nights before going home.
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3 *“You’re totally encouraged to do as much care for your baby as you can. It’s your*
4 *baby, they’re there to support you and to medically [um] jump in if, if need be, but*
5 *don’t expect that they’re there to feed and care for your baby because that’s your*
6 *job.”* (ID34, mother, son with gastroschisis)
7

8 9 **Open access policy**

10
11 Accessing hospitals and specialists after their baby had been sent home could be
12
13 challenging for parents, especially if home was a distance from the specialist surgical
14
15 centre. When problems came up, as they often did, it was hard to know where to
16
17 take their baby. So being given open or emergency access back to the team who
18
19 had looked after their baby, without having to go through A&E first, was really valued
20
21 by parents. ID38’s son had complex needs after his surgery for oesophageal atresia
22
23 and trachea-oesophageal fistula (TOF). She said having open access to the ward
24
25 where they can turn up with their baby and see doctors who know their baby was so
26
27 important. *“I know that won’t last forever but right now the open access is a Godsend*
28
29 *because it means we get seen really quickly.”*
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35 36 **DISCUSSION**

37
38 This study adds valuable insights into the support and information needs of parents
39
40 when their baby requires early abdominal surgery. These surgical journeys are often
41
42 a long haul for baby and parents. Our study highlights the importance of clear and
43
44 ongoing communication between parents and the often large, multi-disciplinary
45
46 teams caring for their infant and points to immediate actions that can improve parent
47
48 experiences and outcomes. Parents value being listened to, encouraged to be a part
49
50 of the care team and supported in finding a role for themselves. They need
51
52 information from the professionals caring for their infant but also recommendations of
53
54 good sources of information to supplement their knowledge, while being mindful of
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3 information overload. For some, encouraging them to seek support from other
4
5 parents is of great value.
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8
9 Previous work exploring parents' experiences of having an infant in NICU or surgery
10
11 has highlighted the importance of good communication and emotional support, giving
12
13 parents support at handover for surgery and pointed to the impact of scanty and
14
15 infrequent information giving^{7 32}. Parents experiences are not only affected by their
16
17 baby's diagnosis and care, but also the ways in which services are organised to
18
19 support families to navigate the systems and maintain a new 'second campus' as
20
21 they look after their baby and continue their lives outside the hospital.³³
22
23

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25
26 Involving and supporting parents is increasingly recognised as an important
27
28 component of providing holistic paediatric care and can help with the uncertainty of
29
30 parenting an infant during critical illness. Parent experiences of NICU point to the
31
32 vital role that neonatal nurses have in engaging with, in particular, mothers and the
33
34 importance of that relationship.³³ Aagaard⁵ discussed the importance of trying to
35
36 strengthen maternal competence, and suggested parent-nurse chat as a
37
38 communication strategy. Our findings provide examples of the ways in which
39
40 encouraging parents to be involved with their infant can be achieved.
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46 Others have described the role of the expert parent³³ and home monitoring
47
48 programmes after cardiac surgery^{17 34}. Studies have indicated that parents are not
49
50 adequately prepared for discharge and are not well equipped to recognise
51
52 deterioration in their child. The positive examples of being prepared for discharge
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3 and supported in becoming the primary carer offer insights into how parents might be
4 supported to manage this transition.
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8
9 Bourdieu's theoretical concepts of habitus and capital are helpful in exploring and
10 unpacking the experiences of parents in these highly technical environments and the
11 value they place on communication, finding their own role and seeking out other
12 parents. They travel a journey from being newcomers in an environment
13 (neonatal/surgical unit) where they are unfamiliar with the socialised norms. They
14 have little capital and no idea how to 'play the game' (what Bourdieu termed the logic
15 of practice) and negotiate the field. There is initially an unequal balance of power.
16 Thus, examples of parents feeling dismissed (or part of the problem) amplify this
17 imbalance. Feeling included in the team caring for their infant and having their
18 expertise (in changing dressings, feeding etc.) supported and celebrated can be a
19 powerful tool in addressing this imbalance. Over time, assisted by good
20 communication from the health professionals and the networks of support and
21 information provided by other parents, parents develop confidence and competency -
22 which Bourdieu might have interpreted as social and cultural capital. Their social
23 capital is extended through the social networks they develop inside and outside the
24 hospital environment, online and in the real world, relating to their new role in caring
25 for their infant. Their cultural capital is extended through the knowledge, expertise
26 and skills they develop to care for their infant. By the time they take their infants
27 home these parents are well on the way to becoming technical experts in their
28 baby's illness and care.
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STRENGTHS AND LIMITATIONS

This is a UK based study that sought to explore the experiences of parents who have an infant requiring abdominal surgery in the first year of life. Interview studies in this field are rare and our study provides rich insights into the emotional and practical impacts of these experiences. While the interviews could not cover all possible conditions, they provide insights that may be generalisable across many different surgical procedures/medical conditions. However, there are several limitations worth considering. We interviewed parents at different lengths of time after their surgery, as we sought to gain insights into the long term as well as short term impacts of these experiences. However, this variation could have influenced parents' recall of events. Parents were asked to describe an intense and often protracted period of their lives in one interview, so it is perhaps inevitable that some details were omitted or compressed. There was also a variety in interviews, with some parents choosing to be interviewed alone, and others in couples. This inevitably means that some interviews are co-produced while others are not. There was little conflict in evidence during interviews although there were inevitable differences of opinion and recall.

CONCLUSION

As babies recover, the potential for parental expertise grows. Our study highlights the vital role of information, both about the condition and about the infant's progress. Health care staff could discuss or direct parents to information sources, seek to empower parents through involving them with their infant's care where possible, and link them with other parents.

A Contributorship statement The study was conceived by MK. All interviews were collected by LH. Analysis was undertaken by LH and LL, with input from MK and AM. LH

1
2
3 wrote the article, with input from the other authors. We thank the members of our parent
4 advisory (PPI) group for their contributions throughout the study.
5

6 **B Competing Interests** Authors declare no competing interests
7

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13 University of Oxford.
14

15 **D Data Sharing statement** Participants were invited to review their transcript and mark
16 any sections that they did not want used before transferring copyright to the University of
17 Oxford for use in research, teaching, publications and broadcasting. These carefully
18 anonymised transcripts form part of a University of Oxford archive which is available to other
19 bona fide research teams for secondary analysis. All authors had access to the all of the
20 data in the study and take responsibility for the integrity of the data and the accuracy of the
21 data analysis.
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Table of Participants

Table 1 Participants					
Condition	Identifier	Parent Mother/Father	Sex of child	Child's age at interview	Intensive or high dependency care admission
Exomphalos*	01	M	m	18 months	Yes
	02	M	f	6 years	Yes
	03	M	f	8 years	Yes
	04/05	M&F	f	8 years	Yes
	12/13	M&F	m	25 years	No
	16/17	M&F	m	13 years	Yes
	19	M	f	16 months	Yes
Necrotising Enterocolitis	41/42	M&F	m	Died age 7 months	Yes
	08	M	m	9 months	Yes
	09	M	m	11 months	Yes
Hernia	23	M	m	6 months	Yes
	26/27	M&F	f	9 months	No
Congenital Diaphragmatic Hernia*	10/11	M&F	m	9 months	Yes
	15	M	m	5 years	Yes
	24	M	m	9 years	Yes
Hirschprung's Disease*	18	M	f	1 year	No
	20/21	M&F	m	4 months	Yes
	22	M	m	16 months	No
	28/29	M&F	m	19 months	No
	39/40	M&F	m	5 years old	No
Gastroschisis*	43/44	M&F	m	5 years old	No
	30	M	m	7 ½ months	Yes
	31	M	m	4 years	Yes
	32	M	f	3 years	Yes
	33/34	M&F	m	3 months	Yes
	36	M	f	19 months	Yes
Short Bowel	37	M	f	6 years	Yes
	35	M	f	7 years	Yes
Jejunal atresia*	25	M	f	4 months	Yes

Oesophageal Atresia with trachea-oesophageal fistula*	38		m	19 months	Yes
Undiagnosed	14		m	6 months	
*Congenital diagnosis					

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COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	p.8
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	p.1 & 8
Occupation	3	What was their occupation at the time of the study?	p.1
Gender	4	Was the researcher male or female?	p.1
Experience and training	5	What experience or training did the researcher have?	p.1
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	NO
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	p.8
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	p.8
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	p.6 & 9
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	p.8
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	p.8
Sample size	12	How many participants were in the study?	p.7
Non-participation	13	How many people refused to participate or dropped out? Reasons?	p.7
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	p.8
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	No
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	Table 1
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	No, but can be
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	No
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	p.8
Field notes	20	Were field notes made during and/or after the interview or focus group?	Yes
Duration	21	What was the duration of the interviews or focus group?	p.9
Data saturation	22	Was data saturation discussed?	p.9
Transcripts returned	23	Were transcripts returned to participants for comment and/or	p.8

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	p.9
Description of the coding tree	25	Did authors provide a description of the coding tree?	No
Derivation of themes	26	Were themes identified in advance or derived from the data?	p.9
Software	27	What software, if applicable, was used to manage the data?	p.9
Participant checking	28	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	P.10-17
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Yes
Clarity of major themes	31	Were major themes clearly presented in the findings?	Yes
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Yes

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.