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The hidden burden of paediatric flexible bronchoscopy

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Competing Interest: The authors have no competing interest relevant to this article.

Key words: bacterial infection, flexible bronchoscopy, paediatric lung disease, protracted bacterial bronchitis; respiratory infection.

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3 Paediatric flexible bronchoscopy is a safe procedure with a low incidence of intra-procedure
4 complications.[1] It is widely used at tertiary paediatric respiratory centres for a range of diagnostic
5 and therapeutic indications. The procedure, however, is invasive and in the UK is usually performed
6 under general anaesthetic. Our team has become increasingly aware of families reporting a burden
7 associated with paediatric flexible bronchoscopy. To assess this we undertook semi-structured
8 interviews with the parents of children who had recently undergone day-case flexible bronchoscopy
9 (consecutive cases) under general anaesthetic at our centre.

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11 The interviews were performed by one individual (JS) using a series of open ended questions. The
12 responses were documented and summarised into themes. We set a minimum sample size of 20 but
13 planned to continue recruitment until analysis showed saturation with no new outcomes being
14 identified.[2] This project was part of a service evaluation. The UK NHS Health Research Authority
15 ethics tool confirmed it was not research so ethical approval was not sought
16 (<http://www.hra.nhs.uk/resources/before-you-apply/is-nhs-rec-review-required/>).

17
18 After 20 interviews, new outcomes were still being identified and so recruitment continued.
19 Interviews 23 to 25 did not identify any new issues and so recruitment halted at that point. Of the 25
20 children, 22 (88%) had recurrent protracted bacterial bronchitis (PBB), two (8%) had suspected
21 malacia and one (4%) was being investigated for haemoptysis. All 25 parents reported the
22 indication(s) for flexible bronchoscopy were clearly explained and potential side effects discussed.
23 Despite this, 19 (76%) parents reported feeling worried or anxious about the procedure. The reason
24 for concern was the general anaesthetic in 15 (79%), potentially having to leave their child in 2
25 (10.5%) and the procedure itself in 2 (10.5%). When asked to rate their level of anxiety on a scale of
26 1 (none) to 5 (severe), the median (range) score was 4 (1-5). Of the 10 children old enough to
27 understand the implications of the procedure, seven (70%) told their parents that they were worried
28 or anxious. The 18 children that attended nursery or school missed a median (range) of 2 (1-7) days
29 as a direct consequence of the bronchoscopy. The 19 parents with jobs had to take a median (range)
30 of 2 (1-8) days carers leave during and after the procedure. Nine (36%) parents reported a financial
31 implication of the procedure in addition missing work. This related to car parking (8 parents), child
32 care for sibling(s) (2 parent) and travel costs (1 parent). Seventeen (68%) children experienced post-
33 procedure side effects including cough, pyrexia, the need for supplemental oxygen and sore throat.
34 In one child, the need for post-procedure supplemental oxygen delayed discharge until the following
35 day and in one other child, temperature and cough was severe enough to require re-attendance at
36 hospital post-discharge.

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3 These interviews identified a significant burden associated with flexible bronchoscopy felt by the
4 child and their family. This related to worry about the procedure, absence from school / nursery,
5 carers leave and additional financial implications. Interestingly, three quarters of parents worried
6 about the procedure despite feeling it had been clearly explained. When counselling families prior to
7 this procedure it may be helpful to specifically address the issues highlighted in this survey to
8 minimise their effects. Further work needs to be undertaken to assess if the burden is similar at
9 different centres and in countries in which paediatric flexible bronchoscopy is undertaken using
10 sedation rather than general anaesthetic. Research is also needed to investigate the role of less
11 invasive techniques such as induced sputum for obtaining lower airway samples in children with this
12 condition.
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20 21 **Patient and Public Involvement statement**

22 Parents reported a burden associated with paediatric flexible bronchoscopy to our team. To assess
23 this, we undertook semi-structured interviews with the parents of children who had recently
24 undergone day case flexible bronchoscopy (consecutive cases) under general anaesthetic at our
25 centre.
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29 30 **Acknowledgments**

31 We would like to thank the families for giving up their time to contribute to this study.
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36 37 **References**

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A single centre survey of parents regarding the hidden burden of paediatric flexible bronchoscopy

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Word Count: 585

Abstract

Although paediatric flexible bronchoscopy is safe with relatively few side-effects, parents frequently report an associated burden. To assess this, we undertook 25 semi-structured interviews with the parents of children who had recently undergone this procedure. Despite reporting the procedure was well explained, parental worry about procedure was common. The procedure resulted in children missing a median of two days from nursery / school and the parents having to take a median of two days carers leave. There was an additional financial burden related to sibling childcare, travel costs and car parking. Clinician should address these issues in pre-procedure counselling.

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4 complications.[1] It is widely used at tertiary paediatric respiratory centres for a range of diagnostic
5 and therapeutic indications. The procedure, however, is invasive and in the UK is usually performed
6 under general anaesthetic. Our team has become increasingly aware of families reporting a burden
7 associated with paediatric flexible bronchoscopy. To assess this we undertook semi-structured
8 interviews with the parents of children who had undergone day-case flexible bronchoscopy
9 (consecutive cases) under general anaesthetic at our centre between May and July 2020.

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11 The interviews were performed by one individual (JS) using a series of open ended questions. The
12 responses were documented and summarised into themes. We set a minimum sample size of 20 but
13 planned to continue recruitment until analysis showed saturation with no new outcomes being
14 identified.[2] This project was part of a service evaluation. The UK NHS Health Research Authority
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18 After 20 interviews, new outcomes were still being identified and so recruitment continued.
19 Interviews 23 to 25 did not identify any new issues and so recruitment halted at that point. Of the 25
20 children, 22 had recurrent (>3 episodes in 12 months) protracted bacterial bronchitis (PBB), two had
21 suspected malacia and one was being investigated for haemoptysis. All 25 parents reported the
22 indication(s) for flexible bronchoscopy were clearly explained and potential side effects discussed.
23 Despite this, 19 parents reported feeling worried or anxious about the procedure. The reason for
24 concern was the general anaesthetic in 15, potentially having to leave their child in two and the
25 procedure itself in two. When asked to rate their level of anxiety on a scale of 1 (none) to 5 (severe),
26 the median (range) score was 4 (1-5). Of the 10 children old enough to understand the implications
27 of the procedure, seven told their parents that they were worried or anxious. The 18 children that
28 attended nursery or school missed a median (range) of 2 (1-7) days as a direct consequence of the
29 bronchoscopy. The 19 parents with jobs had to take a median (range) of 2 (1-8) days carers leave
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Parent Bronchoscopy Questionnaire

- 1) Were the reasons / indications for the bronchoscopy clearly explained?
- 2) Was the procedure and possible complications clearly explained?
- 3) How did you feel when you were told your child need a bronchoscopy?
- 4) Were you anxious / nervous about your child having a bronchoscopy?
 - a. Scale 0-5 (0 not at all anxious, 5 extremely anxious)
 - b. What particular part of the process were you most anxious / nervous about?
- 5) Did your child understand they were going to have a bronchoscopy?
- 6) How do you think your child felt about needing to have a bronchoscopy?
- 7) How much time off nursery / school did your child have to take for the bronchoscopy?
 - a. If so, how much?
- 8) Did you and / or your partner have to take any time off work due to the bronchoscopy?
 - a. If so, how much?
- 9) Were there any other financial implications of the bronchoscopy?
- 10) Did your child experience any side effects after the bronchoscopy?
- 11) How long did it take for your child to fully recover from the bronchoscopy?
- 12) Were the results of the bronchoscopy clearly explained?
- 13) If the results of the bronchoscopy required treatment, was there any delay in this being started?
- 14) Is there anything that could have been done to improve your 'patient journey'?
- 15) Overall how satisfied were you with the paediatric bronchoscopy service? (rate 0-5)