

# Single-centre survey of parents regarding the hidden burden of paediatric flexible bronchoscopy

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**To cite:** Swift JA, Carroll WD, Gilchrist FJ. Single-centre survey of parents regarding the hidden burden of paediatric flexible bronchoscopy. *BMJ Paediatrics Open* 2021;**5**:e000991. doi:10.1136/bmjpo-2020-000991

Received 25 January 2021  
Accepted 28 February 2021

## 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 2 days from nursery/school and the parents having to take a median of 2 days carers leave. There was an additional financial burden related to sibling childcare, travel costs and car parking. Clinicians should address these issues in pre-procedure counselling.

## INTRODUCTION

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

## METHODS

The interviews were performed by one individual (JS) using a series of open-ended questions (see online supplemental file). The responses were documented and summarised into themes. We set a minimum sample size of 20 but planned to continue recruitment until analysis showed saturation with no new outcomes being identified.<sup>2</sup> This project was part of a service evaluation. The UK NHS Health Research Authority ethics tool confirmed it was not research so ethical

approval was not sought (<http://www.hra.nhs.uk/resources/before-you-apply/is-nhs-rec-review-required/>).

## RESULTS

After 20 interviews, new outcomes were still being identified and so recruitment continued. Interviews 23 to 25 did not identify any new issues and so recruitment halted at that point. Of the 25 children, 22 had recurrent (>3 episodes in 12 months) protracted bacterial bronchitis, two had suspected malacia and one was being investigated for haemoptysis. All 25 parents reported the indication(s) for flexible bronchoscopy were clearly explained and potential side effects discussed. Despite this, 19 parents reported feeling worried or anxious about the procedure. The reason for concern was the general anaesthetic in 15, potentially having to leave their child in two and the procedure itself in two. When asked to rate their level of anxiety on a scale of 1 (none) to 5 (severe), the median (range) score was 4 (1–5). Of the 10 children old enough to understand the implications of the procedure, seven told their parents that they were worried or anxious. The 18 children that attended nursery or school missed a median (range) of 2 (1–7) days as a direct consequence of the bronchoscopy. The 19 parents with jobs had to take a median (range) of 2 (1–8) days carers leave during and after the procedure. Nine parents reported a financial implication of the procedure in addition missing work. This related to car parking (eight parents), child care for sibling(s) (two parents) and travel costs (one parent). Seventeen children experienced post-procedure side effects including cough, fever, the need for supplemental oxygen and sore throat. In one child, the need for post-procedure supplemental oxygen delayed discharge until the following day and in one other child, temperature and cough were



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severe enough to require re-attendance at hospital post-discharge.

## DISCUSSION

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

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**Acknowledgements** We would like to thank the families for giving up their time to contribute to this study.

**Contributors** FJG and WDC devised the study. The development of the questions for the semi-structured interviews and analysis of the results was undertaken by JS and FJG. FJG wrote the first draft of the manuscript. All authors helped edit the manuscript and approved the final version.

**Funding** The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

**Competing interests** None declared.

**Patient and public involvement statement** Parents reported a burden associated with paediatric flexible bronchoscopy to our team. To assess this, we undertook semi-structured interviews with the parents of children who had recently undergone day case flexible bronchoscopy (consecutive cases) under general anaesthetic at our centre.

**Patient consent for publication** Not required.

**Provenance and peer review** Not commissioned; externally peer reviewed.

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