



Living and managing with the long-term implications of neonatal chronic lung disease: The experiences and perspectives of children and their parents



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ABSTRACT

Objective: The purpose of the study was to investigate children's perspectives of living with chronic lung disease (CLD) and their parents' long-term experiences of caring for them.

Background: CLD caused by prematurity of birth is associated with continuing respiratory, neuro-developmental and psychosocial issues.

Methods: 10 children (6–15 years old) with CLD and 12 parents were involved in semi-structured qualitative interviews. Data were analyzed using thematic analysis.

Results: CLD was described as 'getting easier over time' and that you 'learnt to live with it.' Expertise was acquired in controlling symptoms and recognizing the onset of illness, despite expressed uncertainty of the nature of the condition. Children experienced difficulties engaging in peer activities and encountered cases of teasing and isolation at school.

Conclusion: CLD was reported as becoming easier over time to live with. Despite this, children experienced challenges engaging in peer activities and families described difficulties interacting with health and education services.

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Introduction

Chronic lung disease (CLD) in premature babies may result in prolonged oxygen dependency. CLD results from the premature, surfactant deficient lung being exposed to damaging influences such as barotrauma from ventilation and infection which results in inflammation and remodeling of post natal lung growth. As a consequence, lung scarring occurs which impedes gas transfer across the alveolar capillary interface. Discharging these infants home with supplemental oxygen rather than them enduring a long stay in hospital is now standard practice, and has been demonstrated to be more cost-effective and better for maternal-infant bonding and wellbeing.^{1–3} It has been shown, however, that infants discharged home on oxygen are more fragile

and have a higher incidence of hospital readmission and health care utilization compared to those who did not require oxygen at home.⁴ These preterm infants as they grow into childhood may have continuing respiratory symptoms, neurologic abnormalities, developmental and functional delay,⁵ educational difficulties, restrictions to social and peer activities and on-going weight and feeding difficulties.⁶

Having a baby requiring supplemental oxygen has been shown to negatively influence maternal wellbeing for many years, with on-going feelings of sadness, hurt, social isolation, lack of self-esteem and having continued worries about future pregnancies.^{7,8} One year after preterm delivery, mothers have been shown to experience stress and anxiety.^{9,10} Mothers of infants with CLD have been found to experience reduced quality of life as a result of sleep deprivation, resulting in a reported increase in stress and depressive symptoms.¹¹ Many of these studies collect data through structured questionnaires, which can be narrow in focus and not account for what matters to parents and their children growing up with CLD. There is little known about parent's experiences and perspectives of caring for their child with CLD *beyond* the infancy period. Children's qualitative

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experiences of having and growing up with CLD are currently absent from the literature. The research team aimed to investigate children's perspectives of living with chronic lung disease (CLD) and their parents' long-term experiences of caring for them.

Methods

Design

As the research team sought the in-depth experiences of parents and children a naturalistic qualitative design was used to gather information through talking directly to people. Semi-structured qualitative interviews were used which supported the interpretive inquiry through allowing an in-depth exploration of the topic and providing the participants with the opportunity to recount their experiences, thoughts and feelings.

Ethical considerations

The project obtained ethical approval through the National Research Ethics Service (13/LO/0241), within the author's institution and from the participating hospital trust's research and development department. Written consent was obtained by the researchers from all the parents who were interviewed as part of the study and verbal or written assent was obtained from the children who took part, as well as parents providing written consent for their children to participate. An activity (board game) to support children and young peoples' understanding of research involvement was used to enhance how information was shared and communicated about the study.¹²

Participants

At the recruiting hospital, a follow-up clinic takes place for children discharged home receiving oxygen therapy. Generally these children are followed up regularly in clinic and by a dedicated oxygen nurse specialist in the home until the age of 3 and discharged if all is well at that point. If respiratory or other problems persist beyond this age then children are followed up until well or are eligible to be transferred to adult services. Parents of children aged over three years with CLD and parents and/or their children aged over six years of age with CLD were opportunistically recruited over a six month period from this follow-up clinic. Families eligible to participate were handed an appropriate study information sheet/s by their clinical team. The information sheet asked parents who were keen to participate to contact the researchers via email, phone or letter. The researchers then contacted these parents on the telephone and answered any questions they may have about the study and arranged a time for the interview. Variation was sought in the sample according to gender, age and severity of respiratory symptoms and recruitment continued until analysis indicated theoretical saturation had been reached. None of the families who volunteered to participate in the study had a child with a reported neuro-development deficit.

Interviews

Semi-structured interviews were carried out exploring the every-day experiences and perceptions of parents and children; how on-going health needs were managed within the family. Interactions with health professionals and sources of condition information and support.

The interviews were conducted in the home setting, children's interviews were held either with their parents or on their own, depending on the child's preference. The interviews with children used a flexible approach depending on the child's preference and ability and was augmented with the use of drawings, spider diagrams and 'thought clouds' to support the dialogue.^{13–15} As the children engaged in these activities the researcher prompted for meaning and to clarify why the child had chosen particular images or text. Interviews were guided by a topic sheet and conducted by researchers (LB, JS) experienced and trained in conducting qualitative interviews and independent of the child's clinical care. The interviews were audio-recorded and transcribed and lasted between 20 and 80 min.

Analysis

Data were analyzed inductively by two researchers informed by the principles of Thematic Analysis¹⁶ and was ongoing during data collection. The pictures and text created by the children were not analyzed as a source of data, instead their verbal descriptions of their drawings and writing were recorded as part of the qualitative interview. This aimed to prevent possible misinterpretation by the researchers and enabled the children to describe and attach meaning to their own data. Line by line coding of the transcripts produced codes which drew on the words and phrases of the participants, these words were maintained throughout analysis in order to ensure participants' words remained central to the interpretation. Themes were then developed which described larger segments of text and the important topics identified in the data. Later phases of analysis were assisted by the use of diagrams to link the themes together and focus on interpretation. Data collection continued until theoretical saturation had been reached and no new data were being collected to further develop the themes.

Results

Twelve parents (11 mothers and one father) and ten children were interviewed (four aged 6–10 years of age; six aged 11–15 years of age). From the interviews a central theme of 'learning to live with it' developed, as well as the sub-themes of 'living with uncertainty,' 'interacting with health professionals and services' and 'stepping back, sitting out and missing out' (Fig. 1). The themes are described in detail below, illustrated with quotes from the transcripts.

'Learning to live with it'

The central theme related to the sense that the children and their parents had learned, over time, to live with CLD and had developed expertise in managing the condition. Parents and their children described that the condition was '*easier to live with as you get older*.' This was in some cases due to the symptoms becoming less severe but was also influenced by the strategies and expertise acquired in managing the condition.

You get used to spotting the signs, so now I know when he's getting worse so we don't go hospital as much because I know what the signs are and I don't, I probably don't leave it as long (Mother J1).

The children and young people described that they just '*got on with it*,' with this seeming to be an active decision to '*not give up*' and persist despite respiratory symptoms. CLD was often contextualized, by parents and children, against other disabilities caused by prematurity; poor mobility, small stature, eyesight problems

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