



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 neurodevelopment 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

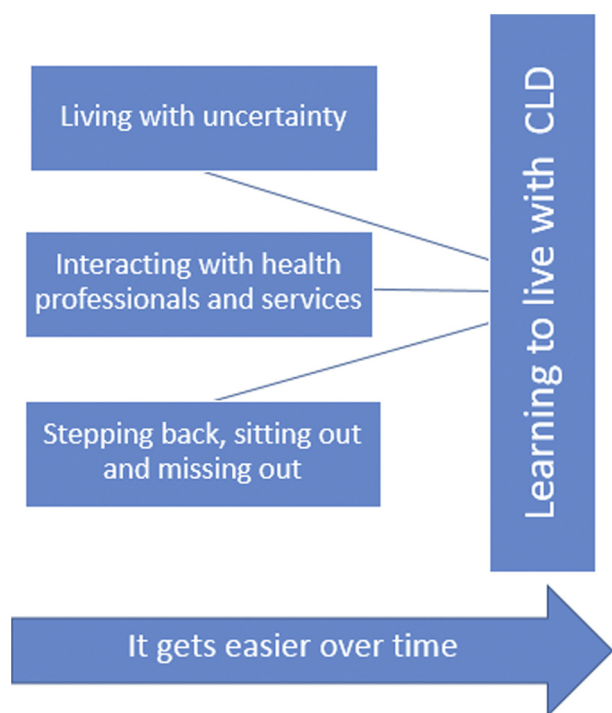


Fig. 1. Diagrammatic representation of findings.

and learning difficulties. The parents reflected on and compared ongoing difficulties to the uncertainty and fear which had overshadowed the first few years of their child's lives.

She's got a lot of medical problems but she's done really well 'cos they said she'd only live 'til she was one to be honest. (Mother L4).

Although parents and their children's accounts included many positive stories of coping with CLD, they also described ongoing periods of uncertainty and worry.

'Living with uncertainty'

Living with uncertainty was characterized by external forces disrupting the equipoise of how the condition was managed within the family. For the parents, uncertainty and worry was associated with their child starting school, being in school or changing schools, where responsibility for condition management was devolved to others seen as less experienced.

We arranged for [oxygen nurse] to go in and speak to the school about it 'cos they were arguing with me all the time 'cos I was keeping her off ... I was keeping her off because I knew she was safe when she was with me. (Mother L2).

Uncertainty was also expressed by both parents and their children when discussing the nature of the condition. Many commented that 'we don't really know what CLD is' and adopted the use of different terms for the condition in different circumstances. Some parents described how they had adopted the descriptor of CLD or Bronchopulmonary Dysplasia to emphasize the seriousness of their child's condition and to get people to 'sit up and take notice.' Several parents described feeling guilty that they did not really understand what underlying condition their child had.

It sounds terrible she's my daughter and I don't really know what she's got ... (Mother, L3).

This uncertainty and confusion also related to how the diagnosis of CLD may have changed over time.

People don't know what chronic lung disease is; I don't know if he [son] still has chronic lung disease. It was chronic lung disease at prematurity, but is that still his condition? (Mother, J2).

Parent's uncertainty over what condition their child 'actually had now' was further exacerbated by the use of the term asthma by health professionals to describe their child's respiratory symptoms and treatment. Many of the parents and children were uncertain whether their child had CLD or asthma or now 'just asthma.' Regardless of this uncertainty the term asthma was used frequently to describe and position the condition as it was seen to be easier to understand.

It's easier [to call it asthma] to be honest because when you say to people its chronic lung, they say what's that? (Mother, L1).

This lack of understanding often left the children and their parents ill-equipped to deal with queries from others about the condition. The label of the condition as a 'disease' was problematic to some families, as it was perceived as something which 'you can catch.'

I used to get the comments like 'no one can go near you 'cos you've got a disease' (Girl, 15 years old, J3).

Many of the mothers discussed the misconception that their child's condition had resulted from them smoking whilst they were pregnant; causing them to feel blamed for their child's condition.

People who don't know about it and you tell them and they go 'I always thought that was a disease, I thought you could only get that with smoke' (Mother, L4).

Parents also expressed anxiety and uncertainty about how their child would fare as they grew up and sought relationships, employment and independence. These concerns did not focus on symptom management, but centered on how their child would 'fit' within a society which was not always understanding of disability.

Yeah, yeah I do yeah, [worry about the future] I think 'cos I know when she's been in school and people have been cruel and I know, I've seen people who can be cruel to people with disabilities (Mother, L4).

Stepping back, sitting out and missing out

For the children their points of uncertainty and concern were shaped by situations which created or reinforced an awareness of their difference to others, causing them to have to step back, sit out and miss out on peer activities.

It feels like I'm just missing out on all stuff, I can't like run or nothing, just sit down, I can't play tag with my mates and all that so it's really hard and upsetting (Girl, 13 years old, L4).

In many cases children learnt to adapt their chosen activities to ones they could take part in on an equal footing to their friends (swimming, drawing, table tennis), but many activities were just 'too much' for some of the children and they engaged in less active lifestyles.

Some children described instances of being teased and excluded by peers, due to their short stature, respiratory symptoms and fatigue. This prompted feelings of sadness and anxiety and caused the children to 'step back' and further exclude themselves from certain activities and social interactions. The exclusion and feeling different to peers had in some cases led to extreme

cases of isolation and bullying, with some children moving schools to leave behind particular groups of children and parents who had caused them harm. The sense of being limited and struggling to join in with peers seemed to decrease over time as children became more competent and confident in negotiating social activities, forging meaningful relationships and being a young person with CLD.

I wouldn't change it, 'cos the challenges I've had to face have made me who I am today and I don't moan every day like, 'Oh I've got lung disease, I was born early,' I just think it was one of those things, you've got to get on with it (Girl, 15 year old, J3).

Increased engagement was also facilitated by the children's developed expertise and mastery of managing their condition and symptoms, with their skills sometimes described as exceeding those of the adults around them.

I'll know what to do, me dad will be like, 'are you ok, are you ok? Have you got your inhaler?', that's all he says, it's like he doesn't know like the little different strategies, like sitting up straight and dropping your shoulders back and, he doesn't like think of all that stuff, where I know what to do, 'cos I've just learnt how to do it, (Girl, 15 years old, J4).

This provided children with increased opportunities to engage with their peers without the presence of their parents.

'Interactions with health professionals and services'

Several of the parents discussed their anxiety as their child grew up and they were 'signed off' from their established contact with the specialist centre ended. This led to them having to rely on services and health professionals who were viewed as having 'less expertise' and familiarity with their child's condition.

Our access [to the specialist ward] finished when he was about three, we got signed off at that point because he was off the oxygen eh ... so I just take him to the GP now. You see they treat it like asthma, so then you are thinking are they doing right from wrong because you know ... I don't think they really understand. They treat it like asthma (Mother L1).

Many of the parents provided powerful accounts of fear, uncertainty and sometimes anger when their acquired expertise was disregarded by health professionals. Although episodes of acute illness became less frequent as the children grew up, many of the parents described instances where they had known that their child was 'not right' and had struggled to get health professionals to acknowledge their concerns.

I'd took him to the GP twice, and I'd took him to the 'out of hours' and they kept telling me he was fine, and I knew in my gut that he wasn't fine. I was sat there with him on my knee thinking, 'what am I gonna do, what am I gonna do' and I drove to the hospital doing his inhaler once a minute and the next thing they've got him in A&E resus (Mother J1).

Over time parents became 'savvy' in deciding which service to access; determined by previous experience and the trust they had in specific health professionals. Children's accounts focused on their planned interactions with health professionals and were more passive, they tended to rely on their parents to 'do the talking' during consultations as they felt ill-equipped to join in the dialogue. This was most evident in the younger children, who felt they lacked the necessary vocabulary or 'fancy words' to join in, some of the young people described gaining skills and confidence over time to enable them to take part in consultations.

As I've got older I can sort of understand what they [clinician] are saying now, and if I don't understand I'm like, 'can you say that in English again' [laughs], when I was younger I didn't feel the confidence to ask him [clinician] the questions (Boy, 15 years old, J2).

A focus on symptom management during consultations and the family's decision to 'just get on with it' could sometimes leave questions unanswered and issues unexplored.

Discussion

There was a strong sense from the children and their parents that CLD had become easier over time to 'live with' and that this had been an active process of learning to manage symptoms and manage the psychosocial impact of the condition on the children's lives. This supports literature from other parents whose children have long-term respiratory conditions and who describe how their ability to cope gradually increases over time.^{17,18} The children and especially the parents' discussed increased competence and confidence in traversing the hurdles and uncertainty they encountered in living with and managing CLD. Ongoing issues were contextualized by parents against the acute first few years of the child's life which had been characterized by expectations of death, critical illness and low expectations for the future. Children who described their condition as 'just a part of me' and not a defining characteristic of who they were, seemed able to identify the development of life skills such as resilience as a result of their experiences with CLD. In the interviews, the children chose to focus on how they overcame their difficulties by adapting over time, rather than focusing on their limitations and problems. The focus on positive adaptation and the development of resilience is in common with findings derived from other chronic conditions of childhood.^{19,20}

The findings from this study have raised the issue that although the health needs of these children may decrease over time, living with CLD is more than the management of physical symptoms. This evidence reflects existing knowledge suggesting that health and education services should acknowledge the wider implications of the condition on school attendance²¹ and building peer relationships.^{22,23} A focus on symptom management during consultations can limit the opportunities to discuss broader knowledge and the strategies adopted by children and their parents to live with a long-term condition.^{24,25} There is increasing recognition that living with a long-term condition involves 'more than' the management of symptoms but is a complex process which will change over time as a young person develops into adulthood.²⁶ Children and young people living with long-term conditions can need support as they grow up to gain skills and coping strategies in managing the wider implications of living with a long-term condition.

Despite the acquired expertise of children and their parents in managing the symptoms of the condition, they continued to experience frustration when their expertise was seen to be disregarded by non-specialist health professionals and schools. This reflects a common experience for parents and children living with long-term conditions,^{17,27–29} where their expertise and acquired competence in illness management can be disregarded by professionals.^{17,30,31} It is suggested that there is a need for health professionals to integrate parents' expertise in managing their child's condition with their own clinical expertise.³²

The families in this study described how, despite acquired expertise in condition management, they lacked an understanding of the underlying condition. The initial explanations they had been given of the condition had faded in memory and had been replaced by uncertainty and a reluctance to ask, after so many years, what the physiology of CLD actually was. The families reports of struggling to describe the CLD condition and 'what the child actually

had' in this study, supports previous evidence that the term 'asthma' can be used imprecisely within this population.³³ There can be an assumption that long-term patients, especially those who have lived with a condition from birth, understand the 'basics' of a condition when they may not.³⁴ A family's use of medical terms and dialogue can imply a level of understanding which should not be assumed and should be revisited along the child's condition trajectory.³⁵ Evidence demonstrates that if young people are well informed about their health condition their confidence and capacity to cope increases³⁰ and that education should be age-appropriate and reinforced as young people grow into adulthood.^{35–37} There is increasing recognition that children should be involved as equal partners in acquiring skills and knowledge about their long-term condition.^{38,39}

The findings from this study highlight the need for further research examining children and their parents' information needs, support needs and interactions with health and education services and professionals over the long-term trajectory of living with CLD. There needs to be more critical examination of the knowledge and information children and their parents possess about long-term conditions. The findings have implications for those clinicians following these children and families in their long-term care.

It is hoped that the findings from this study will be of interest to clinicians working with parents in the pre-birth and neonatal period. This period was portrayed by the parents in this study as particularly stressful and hard and it is hoped that the stories of a positive ongoing trajectory may be of use to those not having yet started on this journey.

Strengths and limitations of this study

This study is believed to be the first to examine children and their parents' experiences of living with the long-term implications of CLD. Strength of this study design was the inclusion of children as participants and the use of qualitative methods which facilitated the children to have a voice and report on their direct experiences of growing up with CLD. These findings must be considered in light of the participating children, being those who were able to verbalize their experiences, and as such did not include those who had complex ongoing co-morbidities and neurological impairments. The study is limited by the families being recruited from one tertiary centre in the North West of England.

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References

- Baraldi E, Carra S, Vencato F, et al. Home oxygen therapy in infants with bronchopulmonary dysplasia: a prospective study. *Eur J Pediatr*. 1997;156: 878–882.
- Hallam L, Rudbeck B, Bradley M. Resource use and costs of caring for oxygen dependent children: a comparison of hospital and home based care. *J Neonatal Nurs*. 1996;2:25.
- Groeneveld M. Sending infants home on low-flow oxygen. *J Obstet Gynecol Neonatal Nurs*. 1986;15:237–241.
- Greenough A, Alexander J, Burgess S, et al. Home oxygen status and rehospitalisation and primary care requirements of infants with chronic lung disease. *Arch Dis Child*. 2002;86:40–43.
- Anderson PJ, Doyle LW. Neurodevelopmental outcome of bronchopulmonary dysplasia. *Semin Perinatol*. 2006;30:227–232.

- Nievas FF, Chernick V. Bronchopulmonary dysplasia (chronic lung disease of infancy) an update for the pediatrician. *Clin Pediatr*. 2002;41:77–85.
- Mann SV. Life after SCBU: the long term effects on mothers at home with a child with bronchopulmonary dysplasia and on home oxygen. *J Neonatal Nurs*. 2000;6:193–196.
- Mann SV. Life after the NNU: the long term effects on mother's lives, managing a child at home with bronchopulmonary dysplasia and on home oxygen. *Neuroendocrinol Lett*. 2004;25:127–132.
- Gracey K, Talbot D, Lankford R, et al. The changing face of bronchopulmonary dysplasia: part 2. Discharging an infant home on oxygen. *Adv Neonatal Care*. 2003;3:88–98.
- Zanardo V, Freato F. Home oxygen therapy in infants with bronchopulmonary dysplasia: assessment of parental anxiety. *Early Hum Dev*. 2001;65:39–46.
- Feeley CA, Turner-Henson A, Christian BJ, et al. Sleep quality, stress, caregiver burden and quality of life in care givers of young children with bronchopulmonary dysplasia. *J Pediatr Nurs*. 2014;29(1):29–38.
- Bray L. Developing an activity to aid informed assent when interviewing children and young people. *J Res Nurs*. 2007;12(5):447–457.
- Hill M. Participatory research with children, research review. *Child Fam Soc Work*. 1997;2:171–183.
- Pridmore P, Bendelow G. Images of health: exploring beliefs of children using the 'draw and write' technique. *Health Educ J*. 1995;54:473–488.
- Punch S. Research with children. The same or different from research with adults? *Childhood*. 2002;9(3):321–341.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–102.
- Beeton K, Neal D, Watson T, et al. Parents of children with haemophilia – a transforming experience. *Haemophilia*. 2007;12(5):570–579.
- Murdoch MR, Franck RS. Gaining confidence and perspective: a phenomenological study of mothers' lived experiences caring for infants at home after neonatal unit discharge. *J Adv Nurs*. 2012;68(9):2008–2020.
- Kim DH, Yoo IY. Factors associated with depression and resilience in asthmatic children. *J Asthma*. 2007;44(6):423–427.
- Chen E, Strunk RC, Trethewey A, Schreier HM, Maharaj N, Miller GE. Resilience in low-socioeconomic-status children with asthma: adaptations to stress. *J Allergy Clin Immunol*. 2011;128(5):970–976.
- Worchel-Prevall FF, Heffer RW, Milner J, et al. A school reentry programme for chronically ill children. *J Sch Psychol*. 1998;36(3):261–279.
- Spirito A, DeLawyer DD. Peer relations and social adjustment of chronically ill children and adolescents. *Clin Psychol Rev*. 1991;11(5):539–564.
- Meijer SA, Sinnema G, Bijstra O, Mellenbergh GJ. Social functioning in children with chronic illness. *J Psychol Psychiatry*. 2000;41(3):309–317.
- Beresford B, Sloper P. Chronically ill adolescents' experiences of communicating with doctors: a qualitative study. *J Adolesc Health*. 2003;33(3):172–179.
- Deater-Deckard K, Bulkley J. Parent concerns in long-term follow-up. *Semin Neonatol*. 2000;5:171–178.
- Halfon N, Hochstein M. Life course health development: an integrated framework for developing health, policy and research. *Millbank Q*. 2002;80(3): 433–479.
- Trollvik A, Severinsson E. Parents' experiences of asthma: process from chaos to coping. *Nurs Health Sci*. 2004;6(2):93–99.
- Salfors C, Hallberg LR. A parental perspective on living with a chronically ill child: a qualitative study. *Fam Syst Health*. 2003;21(2):193–204.
- Jonsson M, Egmar AC, Hallner E, et al. Experiences of living with asthma – a focus group study with adolescents and parents of children with asthma. *J Asthma*. 2014;51(2):185–192.
- Smith J, Cheater F, Bekker H. Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature. *Health Expect*. 2013; <http://dx.doi.org/10.1111/hex.12040>.
- Nuutila L, Salanterä S. Children with chronic illness: parents experiences of care. *J Pediatr Nurs*. 2006;21(2):153–160.
- Kratz L, Udding N, Trahms C, et al. Managing childhood chronic illness: parent perspectives and implications for parent-provider relationships. *Fam Syst Health*. 2009;27(4):303–313.
- Narang I. Long-term follow-up of infants with lung disease of prematurity. *Chron Respir Dis*. 2010;7(4):259–269.
- Bray L, Callery P, Kirk S. A qualitative study of the pre-operative preparation of children, young people and their parents' for planned continence surgery: experiences and expectations. *J Clin Nurs*. 2013;21(13–14):1964–1973.
- Sen BA, Spring H. Mapping the information-coping trajectory of young people with long term illness. *J Doc*. 2013;69(5):638–666.
- Jackson JL, Tierney K, Daniels CJ. Disease knowledge, perceived risk, and health behaviour engagement among adolescents and adults with congenital heart disease. *Heart Lung*. 2015;44:39–44.
- Nicholas DB, Keilty K. An evaluation of dyadic peer support for caregiving parents of children with chronic lung disease requiring technology assistance. *Soc Work Health Care*. 2007;44:245–259.
- King S, Teplicky R, King G, Rosenbaum P. Family centred services for children with cerebral palsy and their families: a review of the literature. *Semin Pediatr Neurol*. 2004;11(1):78–86.
- Carter B, Bray L, Dickinson A, Edwards M, Ford K. *Child-centred Nursing: Promoting Critical Thinking* Sage; 2014.