

Respiratory physiotherapy training for caregivers of children and young people with long-term ventilation: an interview-based service evaluation.

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Abstract

Background

Long-term ventilation has become increasingly utilised for children and young people in the UK who require support with their breathing. Managing children and young people with long-term ventilation at home offers many benefits, but requires comprehensive caregiver training, including for respiratory physiotherapy. Our London teaching hospital recently built a simulation training suite to support caregiver training and education. This service evaluation aimed to assess caregivers' perceptions of the existing physiotherapy training and explore whether simulation training could enhance preparedness in managing physiotherapy needs at home.

Methods

A service evaluation was conducted using qualitative methodology and semi-structured interviews. Caregivers of children and young people with long-term ventilation that had physiotherapy training at the hospital were included. Data were analysed using thematic framework analysis.

Results

Six caregivers were interviewed. They suggested that physiotherapy training prepared them for home following a long hospital admission. Picture and text learning resources were useful; video-resources and caregiver assessments could enhance training. The importance of lived experience to develop clinical reasoning and confidence was highlighted. Caregivers emphasised that the emotional burden of admission negatively affected their ability to learn, supporting the need for post-discharge refresher training. The simulation suite was considered highly valuable, providing an optimal learning environment that was representative of home.

Conclusion

Caregivers were positive about current physiotherapy training at a London teaching Hospital. It could be enhanced by a structured approach, additional learning strategies and by considering contextual challenges. Caregivers felt simulation training would enhance clinical reasoning and preparedness for home.

Introduction and background

The demand for long-term ventilation (LTV) has risen globally among children and young people (CYP) due to advancements in medical management and technology that enable ventilatory support at home. In the United Kingdom, the number of CYP requiring LTV has significantly increased, reaching approximately 2,383 in 2022 (Barker et al., 2022). These CYP often suffer from complex conditions affecting their central nervous, musculoskeletal, or respiratory systems, making them susceptible to secondary complications, including recurrent chest infections (Thrasher et al., 2018). Managing these CYP in the community offers better outcomes and integration of care but requires comprehensive training for caregivers in routine and emergency management (Edwards and Nixon, 2013; Tofil et al., 2013).

LTV initiation generally occurs in paediatric intensive care units or wards in tertiary centres under the care of specialist multidisciplinary teams. These teams ensure caregivers are proficient in daily interventions, recognising respiratory status changes, troubleshooting ventilation issues, and managing emergencies (High et al., 2022). Effective caregiver education is linked to improved survival rates, fewer hospital admissions, and reduced overall costs for CYP on LTV (Sterni and Carroll, 2017, as cited by Boroughs, 2017).

Respiratory physiotherapists, as part of the multidisciplinary team, play a vital role in this training, designing tailored airway clearance programmes, assisting with ventilation weaning, and providing crucial caregiver education (NCEPOD, 2020; APCP, 2020; Simpson et al., 2019). Many CYP with LTV require daily chest physiotherapy to prevent infections and reduce hospital admissions. Community-based respiratory physiotherapy services have proven effective in lowering unplanned admissions and enhancing quality of life in CYP with neurodisability (APCP, 2017).

At a large teaching hospital in London, a multidisciplinary approach is employed for managing CYP with LTV. In 2022, the WellChild Charity funded the Better At Home high-fidelity simulation suite to enhance caregiver training. The suite replicates a CYP with LTV's bedroom at home, using the same equipment found in the community and featuring high-fidelity simulation mannequins for immersive, scenario-based training. Literature suggests that integrating simulation training into caregiver education could enhance preparedness and confidence, provided it includes thorough debriefing to mitigate stress (Boroughs, 2017; Tofil et al., 2013). However, at the time of this evaluation, physiotherapy training at the hospital generally occurred at the bedside or in outpatient clinics. This service evaluation aimed to explore caregivers of CYP with LTV's perceptions of the existing respiratory physiotherapy training and of incorporating high-fidelity simulation training.

Methods

This service evaluation used a qualitative approach to provide in-depth insights into caregivers' experiences and give context-specific, patient-centred evidence that could be used to optimise the training programme for caregivers of CYP with LTV at the hospital (Kolb, 1984; Clapper, 2009). Semi-structured interviews were chosen because they are an effective strategy in healthcare research for exploring personal experiences and perceptions (DeJonckheere and Vaughn, 2019). This flexible format allows for improvisation based on interviewee responses and enhances the depth and richness of data (Kallio et al., 2016). Additionally, interviews are cost-effective, time-efficient, and facilitate rapport, which is important for offering reassurance to caregivers during sensitive discussions.

Parent and Caregiver Involvement

Parents and caregivers of CYP with LTV receiving care at the hospital were included in the evaluation if the child or young person had a physiotherapy airway clearance plan and had undergone training at the hospital. Caregivers were not included if they had received training at another centre, their child was being actively palliated or involved in palliation discussions, or there were ongoing safeguarding investigations. Caregivers were contacted via telephone, with follow-up emails as required.

Data Collection

Semi-structured interviews were conducted following a topic guide that was developed iteratively based on recommendations by DeJonckheere and Vaughn (2019), service evaluation objectives and feedback from clinical experts, a mock interview with a specialist respiratory physiotherapist, and a pilot interview with a caregiver of a CYP with LTV. It included questions on the caregiver's child, the training received, and the potential utility of the simulation suite. It also covered reflections on training experiences, the challenges faced, and suggestions for improvement. Questions were designed to be open-ended to encourage detailed responses and included prompts for further elaboration as required.

The interviews were conducted via Microsoft Teams from the Better At Home high-fidelity simulation suite and included a live virtual walkthrough of the suite. The interviewer showed its features, including the home-like setup, high-fidelity mannequins, and equipment, explaining its purpose and potential applications before proceeding with the questions. Interviews were audio-recorded using a Dictaphone, with backup recordings on Microsoft Teams. Transcriptions were conducted using Microsoft Word's transcription function and anonymised to remove identifiable information. Audio and video files were securely stored in line with GDPR policies and deleted after analysis.

Ethical Considerations

This service evaluation was approved and registered with the Hospital Trust Clinical Audit Team as a service improvement project. Compliance with Trust guidelines on data protection and clinical governance was ensured. Written consent was obtained from all participants, who were informed of their right to withdraw at any time before transcription.

Data Analysis

Framework analysis was conducted by a single researcher in line with the process outlined by Ritchie and Spencer (1994) and Pope et al. (2000). This involved familiarising with the data, developing a thematic framework, indexing, charting, and then mapping and interpreting the data to define concepts, map phenomena, and identify associations between the themes. To enhance rigor, themes and quotations were reviewed by the academic supervisor, with participants providing feedback on the accuracy of findings, to ensure trustworthiness.

Ensuring Rigour

Several strategies ensured the trustworthiness of the data as suggested by DeJonckheere and Vaughn (2019).
Credibility: Verbatim transcription, mock interviews, pilot testing, framework analysis, and validation by participants and the specialist physiotherapist and qualified, experienced researcher.

Transferability: Context-specific findings applicable to wider LTV caseload with some broader applicability.

Confirmability: Awareness of potential biases from the dual role of data-collector as a LTV physiotherapist at the hospital and researcher.

Dependability: Consistent findings based on caregivers' lived experiences, with consideration of external factors such as resource availability and practice changes.

Results

Demographics

Twelve caregivers were contacted, with six successfully participating in the evaluation (*figure 1*). Of the six caregivers who did not participate, three cited time constraints as a reason for declining, one did not provide a reason, and two were unresponsive despite multiple follow-ups. They included four mothers and two fathers. Their CYP were aged between one to four years, all initiated onto LTV within six months after birth (*table 1*). Half of the CYP had a primary respiratory diagnosis, while the other half had either neurological or combined diagnoses. Their physiotherapy plans mostly involved daily nebulisers and percussion, with a significant portion requiring daily home suctioning (*table 1*).

Figure 1: Process of recruitment of caregivers for participation in service evaluation interviews

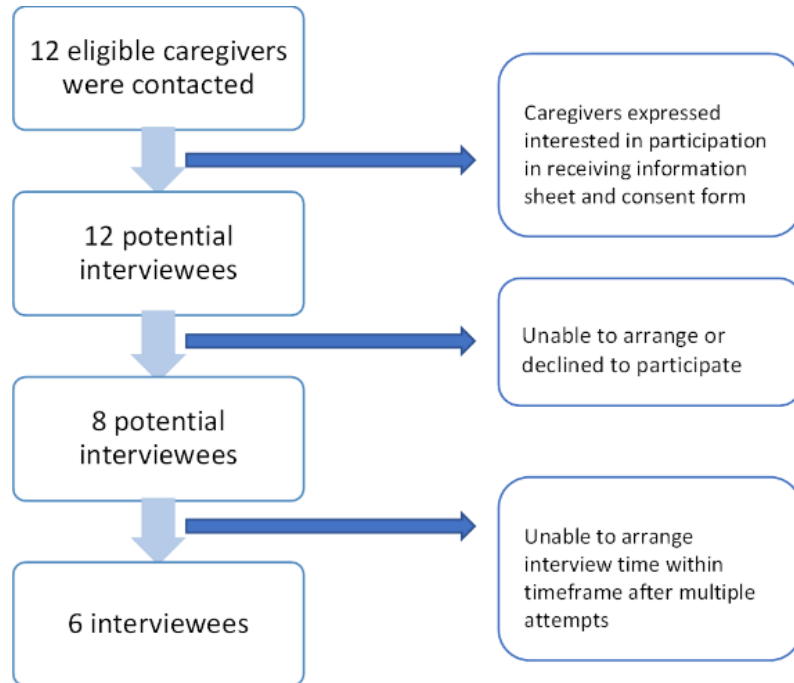
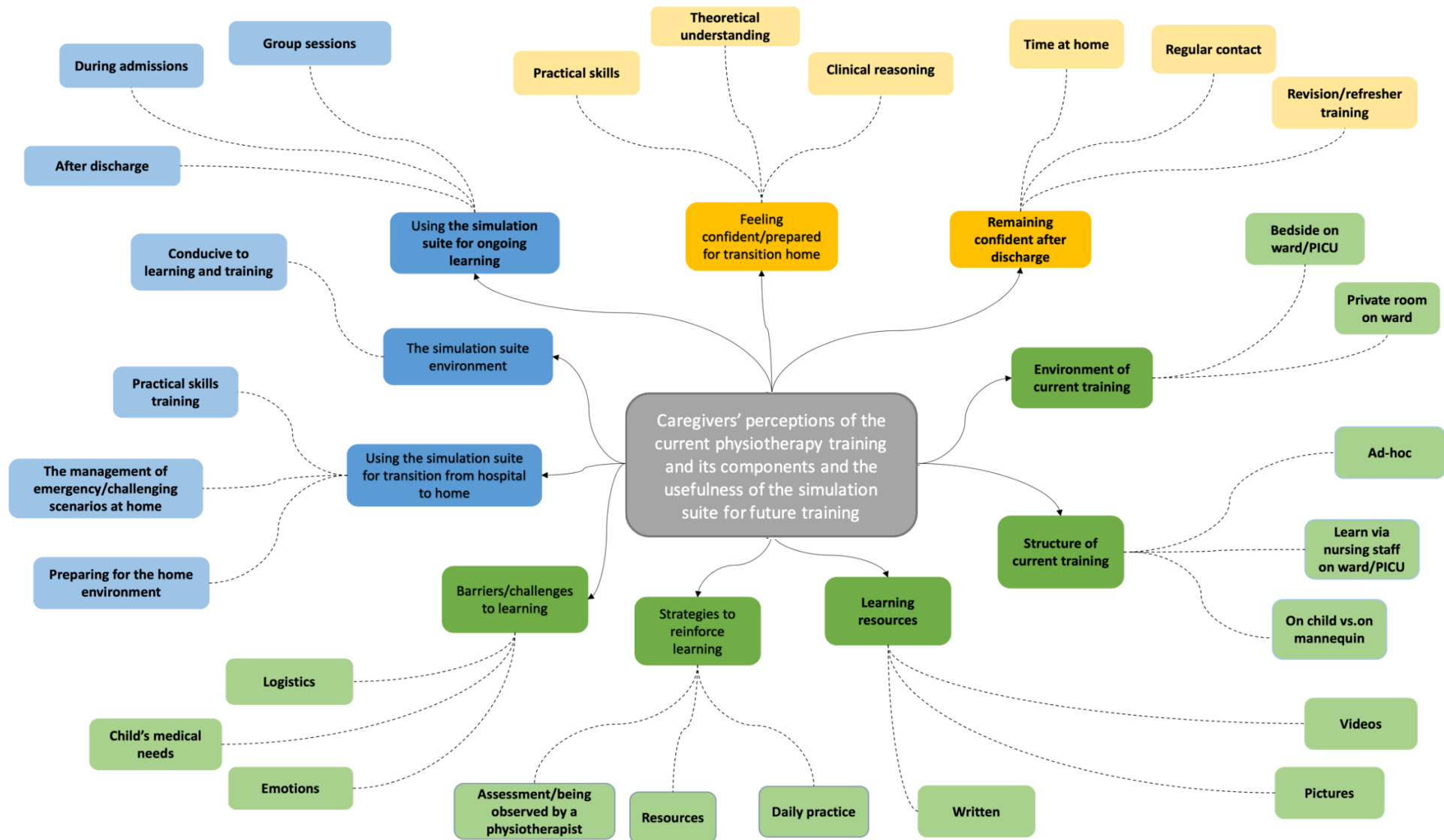


Table 1: Characteristics of caregivers interviewed and their children.

	Categories	Number (%)
Relation to child	Mother	4 (67)
	Father	2 (33)
Chosen method of interview	Face-to-face	0 (0)
	Virtual via Microsoft Teams	6 (100)
Child or young person information		
Gender	Male	4 (67)
	Female	2 (33)
Age at time of interview	< 1 year	0 (0)
	1-2 years	2 (33)
	2-3 years	2 (33)
	3-4 years	2 (33)
Diagnosis	Neurological (CP, CHARGE syndrome, CCHS)	2 (33)
	Respiratory (CLD of prematurity, tracheomalacia)	3 (50)
	Combined respiratory and neurological diagnosis	1 (17)
Type of ventilation	Non-invasive ventilation	3 (50)
	Tracheostomy ventilation	3 (50)
Age started on ventilation	Within 6 months of birth	6 (100)
	> 6 months	0 (0)
Physiotherapy plan	Nebulisers and percussion daily	3 (50)
	Nebulisers daily with the addition of percussion when unwell	3 (50)
	Nebulisers and percussions only when unwell	0 (0)
	MIE or other device	0 (0)
Home suction requirements	Daily suctioning (via tracheostomy and/or NP/OP)	5 (83)
	Nil home suction requirement	1 (17)
Abbreviations: Cerebral palsy (CPP); Congenital Central Hypoventilation syndrome (CCHS); Chronic Lung Disease of prematurity (CLD); Manual Insufflation Exsufflation (MIE); Nasopharyngeal (NP); Oropharyngeal (OP)		

Interviews and Data Analysis

Interviews ranged from 29 to 47 minutes, with caregivers providing detailed feedback on their experiences. Ten major themes were identified, and 27 sub-themes, grouped and colour-coded into three primary frameworks: the effectiveness of current physiotherapy training (yellow), characteristics of the training including strengths and limitations (green), and the potential usefulness of the simulation suite (blue), as displayed in figure 2.



Legend: The effectiveness of current physiotherapy training (yellow); characteristics of the training including strengths and limitations (green); the potential usefulness of the simulation suite (blue).

Figure 2: Concepts map displaying the themes and subthemes organised by colour into the three frameworks of the service evaluation.

The effectiveness of current physiotherapy training

Caregivers generally felt prepared by the physiotherapy training to manage their CYP's needs at home. This was enhanced by having a prolonged hospital stay required for LTV initiation, which allowed for extensive practice and professional support. Many caregivers expressed that, "*feeling fully prepared*" was unachievable due to the complexity of their child's medical needs and the associated anxiety around discharge. One caregiver noted, "*I don't think anybody in our situation can ever feel fully prepared because you just can't. It's not feasible. We had a lot of time learning from nurses and physios, so yes, we felt equipped but also terrified.*"

This sentiment was echoed post-discharge, as caregivers highlighted that real-life experience at home was essential for developing preparedness and confidence. This was linked to the importance of having clinical reasoning, which caregivers described in terms of understanding and applying learned theory in real-life scenarios, with their child, at home. Caregivers suggested that simulation training could provide this valuable "lived experience" in a controlled environment to facilitate skills of clinical reasoning and enhance confidence. One caregiver commented, "*You actually have to live it sometimes to be able to apply it. And, I think, that's where the scenario-room that you're in is definitely going to take it to the next level.*"

Characteristics of the training including strengths and limitations

The environment of current physiotherapy training, which is generally carried out at the CYP's bedside on the hospital ward, paediatric intensive care unit, or paediatric step-down unit, was deemed sub-optimal due to being a high-stress environment and frequent distractions, the most noteworthy being tending to their child. Caregivers also felt that other parents, caregivers and professionals could hear their training, which elicited feelings of judgement and self-consciousness. Figure 3 depicts a word-cloud to display caregivers' descriptions of the learning environment on the ward/PICU.

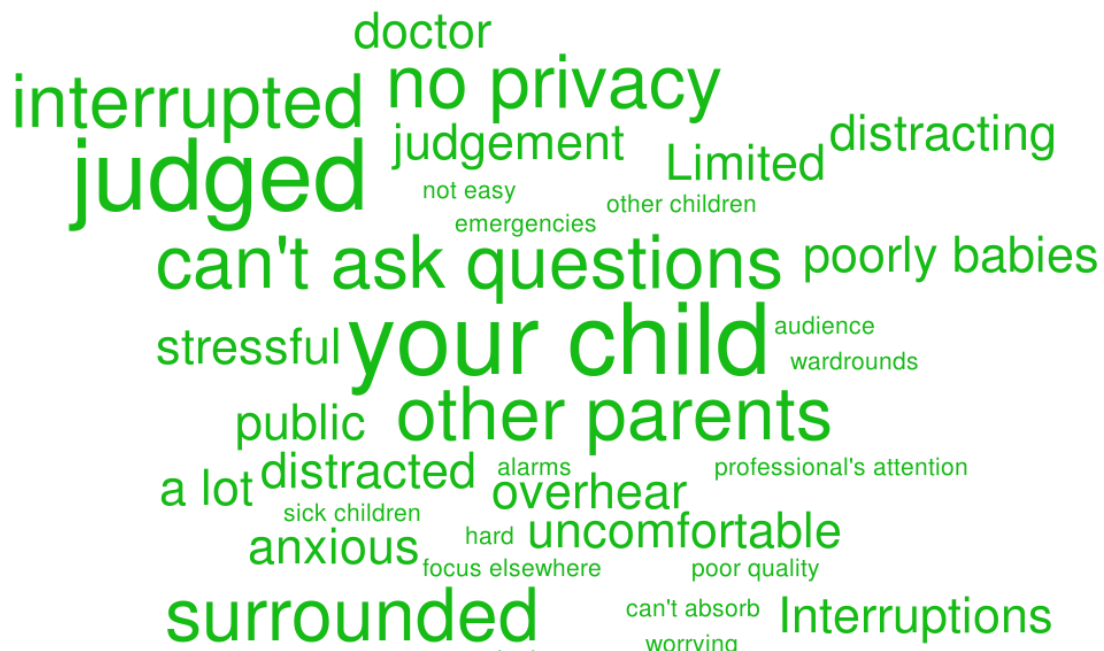


Figure 3: Word-cloud to display caregivers' descriptions of the learning environment on the ward/PICU.

Caregivers commented on the variations in physiotherapists' training approaches, with some receiving initial training on mannequins and others practicing directly on their child. Written and picture resources were helpful for reinforcing learning, but caregivers expressed a need for video resources, particularly for equipment setup and technique. They highlighted the benefits of assessment and feedback from

physiotherapists on their handling and technique for airway clearance, which increased their feelings of confidence and competence.

Caregivers described several challenges to their learning, but a strong subtheme that emerged was the emotional burden associated with their child's hospitalisation, changing medical status, and general anxiety around discharge as significant barriers to retaining information. Many caregivers suggested that post-discharge refresher training, particularly in the form of simulation training, could help overcome this. One caregiver shared, *"It's very stressful being in a hospital and learning how to care for your child in a completely new way. The emotional burden sometimes makes it hard to retain information."*

Potential usefulness of the simulation suite

Caregivers unanimously agreed that the simulation suite would enhance physiotherapy training. They valued the suite's true likeness of their CYP's home set-up and environment, feeling it could bridge the gap between hospital and home, reducing anxiety about discharge. Caregivers highlighted its potential for practicing emergency physiotherapy scenarios, such as mucus plugging, and troubleshooting challenging situations like escalating nebulisers and airway clearance according to their respiratory management plan. They also suggested using the simulation suite for initial physiotherapy skills training and refining clinical skills, describing the environment as far more conducive to learning due to its privacy, calmness, and lack of distractions. *Figure 4* depicts a word-cloud of caregivers' descriptions of the simulation suite as a learning environment. One caregiver commented, *"The simulation suite would be amazing for preparing traumatised parents for the transition home, covering all possible scenarios. It would take some fear out of dealing with a child on long-term ventilation."* Caregivers felt that the simulation suite could significantly improve confidence and competence in managing their child's care at home.



Figure 4: A word-cloud to display caregivers' descriptions of the WellChild Better At Home Simulation Suite

Discussion

This service evaluation aimed to assess the perceptions of parents and caregivers of CYP with LTV regarding the existing respiratory physiotherapy training at one large teaching hospital and the potential usefulness of incorporating the WellChild simulation suite. Key findings indicated that while caregivers generally felt prepared by the current training, there was room for improvement. The main areas identified for enhancement include the training environment, structure, resources, and incorporating simulation training both pre- and post-discharge.

Caregivers reported that the existing training prepared them to manage their child's physiotherapy needs at home, aligning with literature that highlights the importance and positive outcomes of structured caregiver education programmes (High et al., 2022). Caregivers generally felt that training was enhanced by being multimodal, such as written resources with pictures and offering multiple opportunities for supervised practice, but caregivers expressed a need for tools such as video resources and a clear training roadmap, in line with principles of adult learning theory and existing literature (Tearl and Hertzog, 2007; Baker et al., 2016). Videos are low-cost, sustainable, and time-efficient to develop. They offer benefits such as pausing, rewinding, and re-watching and are widely used in the training of physiotherapy students (Noetel et al., 2021).

The potential addition of the simulation suite was unanimously considered a valuable and significant enhancement to physiotherapy training. Caregivers felt it offered a realistic and controlled environment for practising emergency scenarios and refining clinical skills, consistent with principles of adult learning theory and Kolb's experiential learning theory (Kolb, 1984; Thrasher et al., 2018). This aligns with existing literature that supports simulation training to improve caregiver confidence and preparedness in this cohort (Thrasher et al., 2018; Tofil et al., 2013; Whalen, 2020). The suite allows caregivers to practise skills on high-fidelity mannequins and not directly on their child, which is advantageous for learning skills for the first time. However, we suggest that some practical physiotherapy training must be carried out at the bedside, directly on the child (Kolb, 1984, as cited by Thrasher et al., 2018). This prepares parents for the uniqueness of their child's anatomy, behaviour, and responses to respiratory physiotherapy and is essential for the transition home. This would be most useful once caregivers have developed confidence with their skills and techniques in the simulated environment.

Caregiver fatigue and anxiety associated with the hospital stay and having an unwell child were significant barriers to learning and retaining new information. Caregivers of CYP discharged from an acute hospital admission, in a study by Solan et al. (2015), described feeling "in a fog" due to mental exhaustion, uncertainty, and information overload. Incorporating refresher training after discharge, when emotions are less, may enhance physiotherapy training, as in a study by Boroughs (2017) using community-based simulation training in caregivers of CYP with spinal muscular atrophy.

Strengths and Limitations

Strengths of this service evaluation include its qualitative approach for providing in-depth insights into caregivers' unique experiences and perceptions. The use of semi-structured interviews allowed for rich, detailed data collection, and the iterative development of the interview topic guide ensured comprehensive coverage of issues. The feedback and validation steps added credibility to the findings. Furthermore, the service evaluation's focus on practical and actionable recommendations to the service for enhancing training is directly relevant to clinical practice at the hospital.

Several limitations were identified. The small sample of interviewees included only caregivers of children under four years old initiated onto LTV shortly after birth. These CYP make up a large proportion of the LTV caseload. No children with physiotherapy plans including equipment, such as manual insufflation-exsufflation were included. It is possible these children have more time-consuming care-plans which may have impacted their caregivers' availability and willingness to participate, as is consistent with reasons given.

Caregivers assessed the simulation suite based on a virtual walkthrough during interviews, not direct use. While they were shown its features and purpose, their perspectives remain hypothetical. The use of simulation training, the suite itself and the high-fidelity equipment are novel, and this introduces a level of excitement in caregiver responses. To truly explore the usefulness of simulation in physiotherapy training, it must be put into practice and subsequent service-user feedback obtained.

Recommendations for the Future

Future evaluations should expand to include a more diverse caregiver population, incorporating those managing older children and those using advanced physiotherapy equipment. From a research perspective, longitudinal studies examining the impact of simulation training on long-term caregiver confidence and child health outcomes would be beneficial. Additionally, implementing and evaluating the use of the simulation suite for physiotherapy training in practice, followed by a detailed service-user feedback loop, would provide more definitive evidence on its effectiveness and areas for further refinement.

Conclusion

This qualitative service evaluation provided valuable insights into the perceptions of caregivers of CYP with LTV on the current respiratory physiotherapy training at one London teaching hospital. It also highlighted the potential benefits of using a high-fidelity simulation suite in respiratory physiotherapy training with this population. While the current training was effective, incorporating simulation training, structured roadmaps and training videos could significantly improve caregiver preparedness and confidence. The WellChild Better At Home Simulation Suite represents a critical step forward in bridging the gap between hospital and home care, offering a practical and supportive learning environment for physiotherapy. Future evaluations post-implementation of the suite will be essential to fully understand and optimise its impact on caregiver training and patient care.

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Conflict of Interest: No conflicts of interest declared.

Keywords: Long-term ventilation, paediatric, children, caregivers, parents, respiratory physiotherapy, simulation, training, education.

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