

*Original Research***Experiences of caregivers of infants who have been on bubble continuous positive airway pressure at Queen Elizabeth Central Hospital, Malawi: A descriptive qualitative study****Mtisunge Joshua Gondwe<sup>1</sup>, Belinda Gombachika<sup>2</sup>, Maureen D. Majamanda<sup>2</sup>**

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**Abstract****Background**

An innovative, low-cost bubble continuous positive airway pressure (bCPAP) device has recently been introduced in Malawi for the treatment of respiratory distress in infants. While this novel bCPAP system has been shown to be safe and effective in reducing infant mortality, caregivers' experiences have not been investigated. The purpose of this study was to explore experiences of parents and guardians of infants who had been on bCPAP at Queen Elizabeth Central Hospital (QECH) in Blantyre, Malawi.

**Methods**

This was a descriptive phenomenological study that was carried out at the Chatinkha nursery unit and the paediatric nursery ward at QECH, from January to February 2015. Purposive sampling was used to select participants for in-depth interviews. Data saturation was reached with 12 caregivers. Data were analysed using Colaizzi's framework.

**Results**

Caregivers received inadequate, inconsistent, and sporadic information about bCPAP. Student nurses and doctors were best able to answer caregivers' questions and concerns. When their infants were on bCPAP, caregivers felt anxious and fearful. However, upon implementation of bCPAP treatment for their children, the caregivers were satisfied with it. The main sources of psychological stress were limited parent-child interaction and the constraints of prescribed visiting hours. Family, friends, and caregiver involvement in the care of infants provided some psychological comfort.

**Conclusions**

The results show gaps in the information and psychological support that mothers of infants on bCPAP receive in hospital. We recommend that psychological support be given to the mothers of infants on bCPAP at QECH.

**Introduction**

Bubble continuous positive airway pressure (bCPAP) delivers continuous positive pressure (CPAP) to the airways of spontaneously breathing patients throughout the respiratory cycle.<sup>1</sup> It is effective in treating severe respiratory distress due to respiratory distress syndrome, pneumonia, and bronchiolitis in children.<sup>2,3</sup> However, the procedures and environment are stressful for caregivers (parents or guardians). Studies done in Australia and Canada described different oxygen delivery methods as stressful to caregivers, as they create physical barriers between guardian and child.<sup>4,5</sup>

Despite improved child mortality in Malawi, preventable causes of childhood death, such as respiratory failure, remain prevalent.<sup>6</sup> Bubble CPAP was introduced in Malawi to improve the survival of children with respiratory distress.

Communicating treatment plans and supporting caregivers are essential to healthcare. This is a challenge in understaffed Malawian hospitals.<sup>7</sup> Frequently, caregivers receive inadequate health information about a child's illness, management, and prognosis,<sup>8</sup> leading to caregivers having unanswered questions about their child's condition<sup>9</sup> and possible medico-legal actions.<sup>10</sup> The use of bCPAP is new in Malawi and little is known about caregivers' experiences. This study sought to explore the experiences of caregivers of infants who have been on bCPAP at Queen Elizabeth Central Hospital (QECH) in Blantyre.

**Methods**

This was a descriptive phenomenological study, conducted in the Chatinkha nursery unit and paediatric nursery ward at QECH, from January to February 2015. Chatinkha

nursery admits newborn infants aged 0-28 days, and the paediatric nursery admits sick infants, aged 0-6 months. Twelve caregivers of infants who had received bCPAP were interviewed. To maximise the variety of experiences captured, participants were purposively sampled. Written and verbal informed consent was obtained. The caregivers were assured of privacy and confidentiality. They were told about voluntary participation and their right to refuse and withdraw at any time. Permission to conduct the study was granted by the QECH hospital director, the head of the paediatric department, and ward in-charges. Ethical approval was obtained from the University of Malawi College of Medicine Research and Ethics Committee (COMREC).

A semi-structured interview guide (reviewed by clinicians familiar with bCPAP and pretested and revised in the department) was used. Data were collected from one-to-one in-depth interviews. All interviews were conducted in Chichewa and lasted approximately 1 hour. Data saturation was reached with 9 participants whose education level was at primary level and a deliberate effort was made to identify participants of other educational levels. Two participants with secondary-level education and 1 with tertiary-level education were found. The interviews were transcribed and translated into English by a third party soon after each interview. Member checking was done with participants after data collection. Manual analysis of the data was undertaken using the 7 steps of Colaizzi's framework.<sup>11</sup> The themes identified were divided into subthemes and formulated meanings (Table 1).

**Table 1: Themes, subthemes, and formulated meanings emerging from interviews with caregivers of infants who received bubble continuous positive airway pressure (bCPAP) therapy**

Theme	Subtheme	Formulated meanings
Information given to caregivers	Knowledge about bCPAP	Name, function, description of bCPAP
	Type of information	Infant feeding, Infant care and reason, Disease condition
	Sources of information	Doctors, nurses, students
	Time information given	Before bCPAP, after bCPAP
	Significance of information	Understanding of bCPAP, acceptance of bCPAP
Perception about bCPAP	Feelings about bCPAP	Fear, crying, anxiety, worry, disappointment (related to perception of pain inflicted on child and possibility of death)
	Positive impression of bCPAP	Good treatment
	Benefits of bCPAP	Good outcome
Psychological support	Sources of psychological stress	bCPAP machine, parent-child interaction
	Sources of psychological support	Healthcare providers, family members, friends, religious community
	Parental involvement	Parental roles, role significance

## Results

Table 2 shows the sociodemographic characteristics of the 12 participants.

### *Information given to caregivers about bCPAP*

Subthemes that emerged were: knowledge about bCPAP, as well as type, sources, timing, and significance of information received.

Participants knew that bCPAP was treatment to provide extra oxygen to infants who were in severe respiratory distress. One tertiary-educated participant tried to explain the difference between bCPAP and nasal prong oxygen.

*"I think it is the kind of treatment that is provided to babies who have developed the problems with breathing, it is beyond oxygen [nasal prong oxygen], yes, merely oxygen is too small... That means that the baby is critically ill, that is my understanding."* (Participant No. 11)

Most participants with primary level education were unable to name the machine and gave general descriptions:

*"It's oxygen. It was like a car, that sound produced [bCPAP]. It also had lights. It also produces warmed air. It had big tubes, but they were able to fit in each nostril."* (Participant No. 4)

A few participants claimed not to know anything about bCPAP. One primary-educated participant said that she was given no information concerning the infant's condition or about bCPAP:

*"I was not told anything. Maybe they had informed me, but I do not think so."* (Participant No. 7)

The information that participants were given included reasons for bCPAP, feeding of infants on bCPAP through tubes, and care of infants. One of the participants reported that the reason her infant was on bCPAP was that the infant had breathing difficulties:

*"They said that 'we want to administer this oxygen therapy [bCPAP] to the child because of her condition; she is having difficulties in breathing. So we must administer this oxygen therapy'—that is what I was told."* (Participant No. 6)

Participants received information from nurses and doctors. Most participants preferred to get information from doctors and student nurses because they answered their questions, while other nurses would shout at caregivers when approached. One participant narrated:

*"I asked one nurse how much milk to give to my baby and she answered me rudely. She shouted at me 'why did you not ask those who were there? Have you ever seen me before?' I did not like it, but I interpreted that she did not know what to tell me. Then the following day I met a doctor and I asked him, he explained to me, he asked me how many kilograms the baby weighed, and I answered him, then he made his calculations, and he advised me to give the baby 30 millilitres of milk."* (Participant No. 11)

However, several participants, all of whom were over 30 years of age and had primary school education, were unable to differentiate between a doctor and a nurse:

*"It was a nurse; she was putting on maroon top and green pair of trousers especially during the night. I also differentiate nurses from doctors in the way that nurses are females while doctors are males."* (Participant No. 8)

Findings revealed that information was given sporadically, depending on the ward. Most participants from paediatric nursery, and a few from Chatinkha nursery, were given information about bCPAP before commencing treatment:

*"They gave me the information about this type of oxygen [bCPAP] before they put the child on it. They said that 'we want to administer this type of oxygen [bCPAP] to the child because of her condition, as she is having difficulties in breathing. So we must administer this oxygen therapy.'" (Participant No. 6)*

**Table 2: Sociodemographic characteristics of caregivers of infants who received bubble continuous positive airway pressure (bCPAP) therapy**

Characteristic	Categories	Frequency (N = 12)
Age	18-23	5
	24-29	2
	30-35	4
	36-41	1
Marital status	Married	9
	Single	2
	Divorced	1
Education	None	0
	Primary	9
	Secondary	2
	Tertiary	1
Source of income	Employed	1
	Business	5
	None	5
Parity	Primipara	4
	Multipara	8
Child's duration on bCPAP (days)	3	4
	4	3
	5	3
	6	1
	10	1

A few participants from Chatinkha nursery (where mothers do not sleep with their children) reported that they found their infants on bCPAP and information was only provided upon asking:

*"I was not there when they commenced the oxygen [bCPAP] on my child, I found my child already on oxygen [bCPAP]. I did not feel good. When I asked, I was told that they had commenced it because the baby was lacking oxygen."* (Participant No. 8)

Many participants acknowledged that the information helped them to understand their infant's condition and bCPAP treatment. Among the participants who were told about bCPAP before it was commenced, a few participants explained that the information helped them to accept the treatment:

*"I accepted because the doctors told me that in order for the child to get well, the child needed to be treated with this type of oxygen [bCPAP]."* (Participant No. 6)

**Perceptions about bCPAP**

Participants had varying reactions to bCPAP but most reported fear when they saw their infants on bCPAP. They feared that their children may die or be hurt by the machine. Some participants expressed feelings such as broken heartedness, worry, disappointment, and anxiety. One participant explained:

*"I was worried because the tubes in the nose were big, at the same time my child had difficulties in breathing. So I was wondering how effective the treatment would be."* (Participant No. 10)

Most participants had prior misconceptions that oxygen delivering devices (nasal prong and bCPAP) kill. However, when caregivers' infants were on bCPAP, caregivers were satisfied and concluded that it was good. Some participants described it as "lifesaving". One of the participants remarked:

*"People said oxygen was bad because oxygen kills children. This gave me fears and worries. As such, I was asking myself if my child was going to survive on that type of oxygen [bCPAP]. But I had seen how it had worked on my child, who was fine in the end."* (Participant No. 5)

Another participant added:

*"I have seen that it's a good treatment. The way my child was before this treatment, you cannot believe that she is alive today after this treatment. I lost hope for the child. But this treatment has saved the life of my child."* (Participant No. 6)

**Psychological support**

Participants indicated that interrupted parent-child interaction, the three-hourly visiting policy at Chatinkha nursery, and the bCPAP machine itself were major sources of stress.

*"I did not feel good. I just wished I could carry my baby in my arms and breastfeed her, but this was impossible because of that type of oxygen therapy [bCPAP]. I was failing to carry the child because of those tubes. When I wanted to change the nappy, I changed her when she was in the baby cot. There was a tube in the mouth which I used to give the milk."* (Participant No. 8)

*"It affects me. I would love to be together with that baby, to see him all the time; even when sleeping we should sleep together. But this idea of sleeping somewhere and the baby somewhere else affects me psychologically to say the truth, but what else can I do?"* (Participant No. 1)

*"Sometimes you fear that the child is not going to be fine because other children die on that oxygen [bCPAP]. But I thank God because by his grace, I have seen my child getting out of it alive."* (Participant No. 4).

Some participants acknowledged the encouragement and reassurance they received from healthcare providers as important to them while they were caring for their sick infants on bCPAP. One participant said:

*"The healthcare provider reassured me that I should just leave everything in hands of God Almighty, and that I should not cry because the child will be fine."* (Participant No. 9).

Another participant added that:

*"There was one nurse who explained to me as I asked her why my child was breathing like that. She told me that it may be due to problem of the lungs which are not mature due to prematurity. So don't worry your child will be fine."* (Participant No. 8)

Some participants got support from family members and friends through visiting, praying, encouraging, and reassuring,

which influenced the caregivers to accept the treatment and cope well with the situation. One participant said this:

*"I shared my fears about the treatment [bCPAP] with my mother, my husband, and my friend who also had her baby on bCPAP. My mother said that I should put everything in God's hands... While my husband said that I should not worry... My friend also reassured me that her child was also on the same treatment and had improved."* (Participant No. 4)

Participants reported that they were less anxious when they were able to undertake a parental role, such as feeding, changing nappies, turning the baby, tepid sponging, and reporting any problem to nurses. One participant narrated:

*"When the infant was on the machine [bCPAP], he would remove the tubes while crying or fight the tubes out. I would then notify the nurses and doctors that the baby had removed the tubes, and they would come and fix them. This made me feel good."* (Participant No. 2)

Another participant said:

*"I was going to give breast milk to the baby, change the nappy, turn the baby, bath the baby, and inform the nurse of any problem. Coming closer to my child made me worry less."* (Participant No. 12)

Another participant added:

*"I helped to do tepid sponging when the body was hot. I also breastfed the baby."* (Participant No. 5)

## Discussion

Some of the mothers were young first-time mothers, which may have made it difficult to cope with the extra responsibility of caring for a sick infant on bCPAP.<sup>12</sup> First-time mothers need extra guidance and reassurance concerning their infants' condition and the bCPAP intervention.<sup>12</sup>

Most mothers knew that bCPAP provides extra oxygen to infants in severe respiratory distress. Some were unable to name the machine, while some did not know anything about it. This implies that the information given to caregivers was inadequate, especially for their level of education. Reports of another study showed that illiteracy affects a parent's ability to understand and remember information and describe a child's symptoms; it limits her ability to participate in medical decisions.<sup>13</sup> Fear concerning bCPAP treatment may mean that parents do not remember any information given to them. Similarly, a study conducted in the United Kingdom reported that parents under stress are unable to remember most conversations.<sup>14</sup> As such, it is important to reinforce and repeat information and allow time for parents to ask questions to clarify their understanding so that they meaningfully participate in the care of their children.<sup>15</sup>

Shortages of nurses, congestion, and workload also contribute to inadequate dissemination of information by healthcare workers.<sup>7</sup> Healthcare workers focus on providing physical treatments, and therefore educating family members may not be a priority. These findings are similar to reports from Canada, California, Greece, and Denmark, where parents of infants in neonatal intensive care units (NICU) and paediatric units face challenges related to access to information; disclosure about diagnosis, treatment and prognosis; and a lack of control over the care of their children.<sup>16-19</sup> Inadequate communication can compromise compliance to treatment.<sup>8</sup>

In our study participants did not receive standard information. Standardised information about treatment plans reduces variation, improves quality, prevents errors

of omission and misinterpretation, saves time, and reduces redundancies in care.<sup>20</sup> In this study, caregivers received information from either a doctor or a nurse. However, caregivers had difficulties differentiating nurses and doctors, meaning that healthcare providers may not have introduced themselves and may not have worn prescribed uniforms and identity cards. The caregivers' levels of education may also have affected this. A study from Hong Kong found that healthcare workers often do not introduce themselves or describe their roles to patients.<sup>21</sup> Confusion among patients, guardians, and caregivers is compounded when nurses do not wear uniforms.<sup>22</sup>

Caregivers from the paediatric nursery ward received information before commencing bCPAP. In Chatinkha nursery, information was usually received after commencing bCPAP. This is because in Chatinkha nursery, caregivers stay on a different ward and visit their children every 3 hours. When a neonate's condition deteriorates, healthcare workers must implement lifesaving procedures. In the paediatric nursery, caregivers are always available and are informed before starting bCPAP. These findings are contrary to recommendations that informed consent must precede any treatment or procedure.<sup>23</sup> In this study, the caregivers who found their infants already commenced on bCPAP were more stressed than their counterparts. A South African study reported that parents who were not told about CPAP had high levels of stress.<sup>24</sup> It is the responsibility of health workers to give adequate information when possible, before any treatment, to reduce stress. Most participants acknowledged that the information given was helpful in understanding their infant's condition and bCPAP.

Perceptions about bCPAP treatment varied, but common to most participants was the fear of injury to or death of their child when bCPAP was initiated. In a different Malawian study, caregivers believed oxygen therapy was dangerous, as they had observed or heard of patients dying.<sup>25</sup> Conversely, caregivers also described bCPAP as a "lifesaving treatment". This finding is similar to studies done elsewhere that found that mothers of infants cared for in NICUs perceive technological interventions as ensuring survival.<sup>5,26,27</sup> In addition, the caregivers also thought that the experience of having their infants on bCPAP cleared the misconceptions about bCPAP's lethality.

The caregivers in this study described the disruption of parent-infant bonding caused by bCPAP treatment and Chatinkha nursery's visiting policy (every 3 hours) as major sources of stress. Oxygen delivery methods create a barrier between a mother and an infant such that mothers are afraid to hold their babies, are unable to see their babies' faces, and skin-to-skin contact is interrupted.<sup>4,5</sup> Physical contact between mother and child is necessary to develop parent-infant bonding, facilitate infant brain development, reduce the level of pain and stress for the child, and reduce depression levels for mothers.<sup>28,29</sup> Furthermore, the caregivers reported that the tubing on bCPAP machines prevented contact between them and their children. Healthcare providers must encourage physical contact between mother and infant when bCPAP is being utilised. In this study, healthcare workers demonstrated this by welcoming parental participation in the care of their infants, which was helpful. However, studies have shown that parents lack support and guidance from nurses on how to participate.<sup>8,30</sup> It is therefore important that nurses offer support and clearly define caregivers' roles in child care.

The sound of the machine, its lights, and the size of the nasal tubes were alarming to caregivers and caused stress.

This was also found in studies done in Canada and Australia, where the equipment necessary for oxygen delivery was a major cause of fear among mothers, as they were worried that their children may be hurt and the sound that the machine produced was terrifying and overwhelming.<sup>4,5</sup> This suggests a need for healthcare providers to explain the treatment plan comprehensively, which may include benefits, risks, functions of the machine, and potential complications, as this will prepare caregivers psychologically and help them adapt better to the situation.

This study revealed that caregivers received psychological support from healthcare workers, family members, and friends. Caregivers perceived psychological support from family members as vital to their psychosocial well-being. This suggests that the healthcare providers should ensure close family members, like spouses, have a good understanding of bCPAP treatment so that they can support guardians properly. Caregivers also appreciated encouragement offered by fellow caregivers, which made them less anxious. This can be formalised in hospitals by introducing support groups so that caregivers of infants with similar conditions and receiving similar treatment should offer psychological support to each other.

Religion was another source of support for caregivers. Religion has the benefit of empowering individuals by connecting people to their communities and to their spirituality, which might bring about psychological stability.<sup>31</sup> In this study, participants felt happy when they participated in the care of their infants, and this helped reduce their stress. Participants were involved in feeding, changing nappies, cleaning, turning, bathing, and reporting problems to nurses. Involving caregivers is encouraged in child care, as family members are partners and collaborators in child health nursing.<sup>32</sup>

### Limitations

The study was conducted at QECH; hence findings will be applicable to QECH only. However, the findings may provide useful insight in improving experiences of caregivers whose infants are on bCPAP in other settings. This study only included participants whose infants had improved on bCPAP, and this may not represent the experiences of those whose infants died. Another study to explore experiences of caregivers whose infants died on bCPAP is recommended. Another limitation is that interviews were conducted while caregivers were still in hospital. This may have an impact on findings, as caregivers may not communicate their true experiences for fear that such information may affect the care of their infant.

### Conclusions

This study has revealed gaps in support provision to caregivers of infants on bCPAP at QECH, in terms of information provided and psychological care. The study has highlighted different feelings and perceptions the caregivers have concerning bCPAP. All caregivers seemed pleased that their babies were improving with bCPAP. The study has also revealed that family members, friends, and parental involvement in the care of their infants were among stronger sources of psychological support, when compared to healthcare providers. These findings can guide the development of specific interventions to promote psychological health among caregivers with sick infants on bCPAP.

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### Competing interests

There are no financial and non-financial conflicts of interest in this study.

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