Outcomes of home-based oxygen therapy in children discharged from Kenyatta National Hospital, a retrospective cohort study

Adil Waris, Varsha Vekaria-Hirani, Monica Saulo

Abstract

Background: Home based oxygen therapy (HOT) is often required in children with chronic respiratory conditions. Whereas this has become a standard practice in resource rich regions of the world it remains a major challenge in sub-Saharan Africa. Benefits of HOT include shorter duration of hospital stay with both reduced nosocomial infections and health care costs. It further allows the family to be economically productive as the child recuperates at home and not in a hospital setting. There remains in Kenya a large number of children in public hospitals who require HOT but due to its cost restrictions are unable to be discharged home, and so we initiated the first private funded program in 2016 whose outcomes are yet to be evaluated.

Study objectives: The objective of this study was to determine the outcomes and challenges among children discharged from the Kenyatta National Hospital on HOT.

Methods: This was a hospital based retrospective cohort study carried out among 22 children aged less than 16 years from January 2016 to April 2020. A standard questionnaire was used for data collection. Data was stored and analysed in MS-EXCEL and STATA 12.

Results: A total of 22 children were sequentially enrolled for this program of which 10 (45.5%) have been successfully weaned off oxygen in a home setting. The overall mortality was 8(36.4%) of which 7 (87.5%) died in hospital after readmission and 1(12.5%) died at home. In the patients who died there was no statistical differences in term of their ages, sex, underlying lung pathology, distances from hospital, housing structure types or caregiver ages as compared to those who survived. The mean duration of hospital stay prior to discharge on HOT was 112 days and the mean duration of HOT use was 117 days. Major challenges faced by the caregivers included power outages at home, delayed initiation of HOT due to inability to pay hospital bills, increased electricity costs at home and inability to pay for transport to clinic visits whilst dealing with fears of "oxygen addiction in their children". The authors dealt with poor quality concentrators, unanticipated maintenance costs, increased oxygen cylinder use and difficulty in reaching slum dwellings. The lack of pulse oximeters at home led to either overuse or underuse of oxygen flow in almost all patients.

Conclusion

This has been a successful beginning of a sustainable HOT program with minimal complications and no HOT related morbidity and mortality allowing needy children to be discharged earlier. The challenges we faced were not insurmountable and we feel this program can be similarly adopted in other resource restricted settings.

Keywords: Hypoglycaemia; Hyperglycaemia; gluconeogenesis; Glycogenolysis.

Adil Waris,Aga Khan University Hospital, Nairobi. **Varsha Vekaria-Hirani**,M.P. Shah Hospital, Nairobi. **Monica Saulo**,Aga Khan University Hospital, Nairobi.

Corresponding author: Adil Waris, e-mail: warisadil@hotmail.com

Introduction

Home based oxygen therapy (HOT) is often required in children with chronic cardio-respiratory conditions. Whereas this has become a major practice in resource rich regions it remains a major challenge in sub-Saharan Africa1. Benefits of HOT includes shorter duration of hospital stay with both reduced nosocomial infections and health care costs. It further allows the family to be economically productive as the child recuperates at home and not in hospital1,2. Home based oxygen therapy is indicated in primary lung diseases such as bronchopulmonary dysplasia, bronchiolitis obliterans, cystic fibrosis, interstitial lung disease and primary cardiovascular diseases such as congenital heart conditions and pulmonary arterial hypertension among others3. The HIV epidemic in sub Saharan Africa has led to an increase in acute, chronic and repeated lung infections resulting in bronchiectasis and/or pulmonary arterial hypertension which in turn interferes with alveolar gas exchange4. This has strained the health systems as more children require HOT.

Chronic hypoxia affects the cardiovascular system, which eventually causes pulmonary vasoconstriction in unventilated areas in an effort to maintain the ventilation/perfusion ratio. Generalized alveolar hypoxia causes pulmonary hypertension as the smooth muscle of the pulmonary arteries hypertrophy leading to eventual co pulmonale with reduced myocardial contractility

and right heart failure. Increased work of breathing consumes more calories which interferes with growth which is vital in the child's overall rehabilitation. Chronic hypoxia also leads to decrease in quality of sleep and poor neurological and psychomotor development3.

Oxygen is used in these children to maintain levels in acceptable ranges based on the age and respiratory conditions and is measurable easily with a pulse oximeter5. Discontinuation of oxygen is based on clinical assessment and oxygen saturation measurements6. Oxygen can be delivered to patients on HOT in two main ways; with a cylinder and/ or concentrator. Cylinders are widely available and do not require electricity but need to be refilled almost weekly depending on use and thus costly, they are also heavy and have an increased fire risk3. Locally available concentrators work with electricity and do not require regular maintenance but are expensive (800 to 1500 US dollars) to buy, they are not portable and operate with continuous electricity.

A study done in Malaysia by Norzila et al. showed 71 children benefited from the HOT program by shortening hospital stay, reduced costs and preventing prolonged separation of families2. HOT programs are not readily available in sub-Saharan Africa and this first private donor program was initiated in January 2016 in Kenya. At any given point in time, there were between 4-10 children who were ready to be discharged from Kenyatta National Hospital (KNH) but required HOT. Children who had stayed in hospital the longest and would benefit from HOT were identified and enrolled in the program. Every child was discharged with a medium oxygen cylinder (3400 liters) or concentrator and with a small backup oxygen cylinder (1360 liters). A trained nurse accompanied the child and caregiver to the home and set up the HOT at no cost to them. Well-wishers contacted by the team donated to the costs of concentrators, refills of cylinders, maintenance of equipment and transport. As children improved and did not need oxygen, the concentrators were then re-used for the next child. A 24-hour mobile phone service was available to the caregivers in case of any concerns. Caregivers would have emergency numbers of the nurse and company that would deliver fresh oxygen cylinders to their door steps in the slum dwelling. The nurse would review the children at home on day 7, 14 and thereafter every month. Hospital visits to the doctor were on a 6-8 weekly basis. The caregivers were trained on the use of the concentrator, cylinder as a backup, how to adjust oxygen flow and to look out for emergency respiratory signs (respiratory rate, cyanosis and chest wall indrawing). They were not provided with a pulse oximeter.

Children in the past have ended up staying in hospital for long durations of up to 9 months, waiting for resolution of oxygen dependency whilst increasing financial burden. They were admitted to general wards, often two children on the same bed with huge risks of further nosocomial respiratory infections and reduced chances of recovery. The HOT equipment is very expensive and unaffordable by most patients admitted to KNH and hence enrolling them in the donor program allowed early discharge. Locally there are no studies done on HOT and this will be the first to assist us understand benefits and challenges faced and to improve the care of these children in future.

Materials and Methods

A hospital based retrospective cohort study, carried out over a period of 4 years from January 2016 – April 2020 at KNH, the national teaching and referral hospital in Nairobi, Kenya. Children aged upto 16 years are admitted in the paediatric section of the hospital and cared for by paediatric residents and consultants. More than 90% of the children are referred from peripheral hospitals. Around 450 children are admitted in a month to the wards and 250 neonates to the newborn unit. The private donor program is run by approaching well-wishers to assist in contributing to HOT equipment and maintenance costs. The first author initiated and heads the program assisted by two volunteers. Children identified by the attending clinician with chronic cardio respiratory disease and oxygen dependency were enrolled into the program. The nurse would then contact caretakers to assess the home environment and any special needs it may have and to begin teaching on the use of HOT equipment, understanding danger signs prior to discharge from the hospital. Each caretaker was administered a questionnaire (Appendix 1) to identify challenges after two months on HOT.

Objectives: The primary objective of the study was to determine outcomes of children enrolled in the HOT. The secondary objective of the study was to determine challenges faced by caregivers and the authors in HOT.

Subjects: All 22 Children aged 0 days to 16 years requiring HOT and ready for discharge according to the ward consultant at the KNH paediatric wards and newborn unit were enrolled in the study.

Data collection and analysis: A questionnaire was used for data collection and analysed using MS-EXCEL and STATA 12. Frequency and percentages were calculated for categorical variables. Mean was calculated for normal distribution and skewed data was expressed as median. Tests of association between outcome variables (survival) and independent variables were carried out by chi-square test and binary logistic regression for normal distribution. Qualitative data was analysed in emerging themes.

Ethics: The study was approved by the KNH/UON ethics committee (P860/10/2019).

Results: A total of 22 children have been discharged from hospital on this program. The mean age was 44 months. Table 1 shows the sociodemographic characteristics and HOT use of the enrolled children.

Characteristic		**Frequency (%)**
		N=22
Age (months)	0 - ≤ 12	10 (45.5)
	>12	12 (54.5)
Sex	Male	11 (50.0)
	Female	11 (50.0)
Residential	In Nairobi city	12 (54.5)
	Out of Nairobi city	10 (45.5)
Type of house	Mud	1 (4.5)
	Stone	15 (68.2)
	Iron sheet	6 (27.3)

Home distance from KNH (kilometers	0 - ≤ 10	3 (13.6)
	>10 - ≤ 20	8 (36.4)
	> 20	11 (50.0)
Caregiver's age (years)	18 - ≤ 25	8 (36.4)
	>25	14 (63.6)
Caregiver's education level	None	0 (0)
	Primary	4 (18.2)
	Secondary	12 (54.5)
	Tertiary	6 (27.3)
Duration of hospital stay (days)	0 - ≤ 60	5 (22.7)
	>60 – ≤ 180	15 (68.2)
	> 180	2 (9.1)
Duration of HOT (days)	0 - ≤ 90	7 (31.8)
	> 90 – ≤ 180	4 (18.2)
	> 180	11 (50.0)
Readmissions whilst on HOT	0	14 (63.6)
	1	5 (22.7)
	2	1 (4.5)
	3	2 (9.2)

Table1: Sociodemographic characteristics and HOT use of the enrolled children.

The median age of the caregiver was 28 years. Only 1 (4.5%) child was HIV positive. The mean and median duration of hospital stay prior to discharge on HOT was 112 and 108 days respectively.

Figure 1: Type of houses the enrolled children lived in

(a) Mud house (b) Iron sheet house (c) Stone house.

The children came from different home settings as shown in Figure 1, 1(4.5%) of them stayed in a mud house, 15(68.2%) in stone and 6(27.3%) in iron sheeting houses.

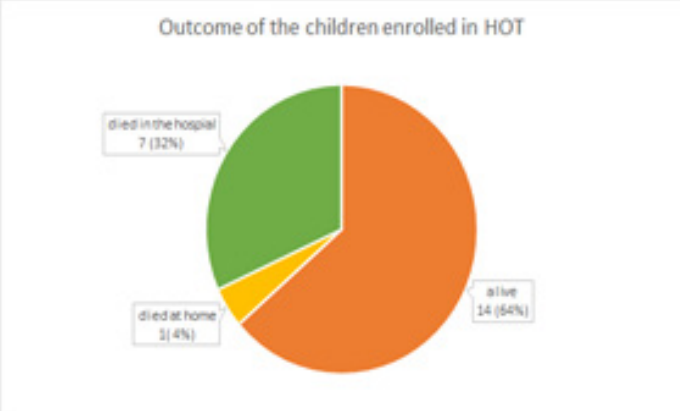

Figure2: Outcome of the enrolled children.

The overall mortality was 8(36.4%) of which 7 (87.5%) died in hospital after readmission and 1(12.5%) died at home but not due to lack of available HOT. The deaths were not significantly different between both genders, patient's age or caregivers' ages. The odds of survival when distance from KNH to home is > 10 - ≤ 20 km is 3.0 and this reduces to 2.6 when the distance is > 20 km but not statistically significant (p= 0.07). There was no survival benefit in any type of housing structures (p = 0.26). The odds of survival are the highest at 5 when the caregiver had a tertiary level of education but this was not statistically significant (p= 0.64). Currently 10 (45.5%) of the children have been discharged off HOT and are well.

There were 8 (36.4%) children who were readmitted to hospital whilst on HOT of these 7(87.5%) were due to deterioration of their medical condition and 1(12.5%) due to poor electricity supply at home for the concentrator.

Among the children discharged on HOT, 19 (86.4%) were primarily discharged concentrators and 3(13.6%) on cylinders with pressure regulators. Both groups had a secondary emergency/ transport oxygen supply in the way of a small oxygen cylinder.

The mean and median duration of HOT use was 343 and 183 days respectively. The total hours of oxygen consumption whilst at home for all children was 94815, with a mean and median of 4332 and 2736 hours respectively. The total minimum and maximum oxygen requirement were 144 and 16296 hours. Continuous use of oxygen more than 16 hours per day was required in 15(68.2%) whilst 7 (31.8%) required oxygen < 8 hours per day and none required oxygen use of between 8 to 16 hours.

Respiratory condition	**Frequency**	**Outcome (Alive)**
	n=22	**(proportion %)**
Primary Lung Pathology		

Bronchiectasis and	Interstitial lung disease (ILD) and HIV	1	1 (100%)
	Pulmonary tuberculosis and ILD	1	0 (0%)
	Bronchiolitis obliterans and infective endocarditis	1	1 (100%)
ILD		3	2 (66.7%)
Bronchiolitis obliterans		1	1 (100%)
Bronchopulmonary dysplasia		3	3 (100%)
Sarcoidosis		1	1 (100%)
Laryngo-bronchomalacia and pulmonary tuberculosis		1	0 (0%)
Cerebral palsy and aspiration pneumonia			1 (100%)
Secondary Lung Pathology			
Pulmonary arterial hypertension (PAH	Hydrocephalus	1	0 (0%)
	Congenital heart disease	4	2 (50.0%)
	Kyphoscoliosis and cerebral palsy	1	1 (100%)
	Celiac disease	1	1 (100%)
	Osteogenesis imperfecta	1	0 (0%)
Tracheobronchomalacia	Down's Syndrome	1	0 (0%)

Table 2: Respiratory conditions of the enrolled children on HOT and their outcomes.

Most patients had more than one diagnosis and this is summarized in Table 2 with their outcomes. PAH was present in 8 (36.4%) and was associated with various other conditions. The odds of dying from primary versus secondary lung pathology was 1.5 and 2.0 respectively but not statistically significant (p= 0.75).There were three emerging themes of challenges faced in delivering HOT.

Patient Factors: The caregivers of these children were young, in view of the educational level and understanding, it was difficult to ensure compliance with oxygen use for durations prescribed. Coming from a resource poor setting, payment of hospital bill before they were initiated on HOT delayed discharge. The caregivers had to pay for transport for clinic visits and a number could not afford this, hence clinic visits were not as per the appointments and the nurse had to frequently remind them and occasionally pay for transport from the donor fund. This reduced the patient doctor interaction and the nurse had to telephonically inform the doctor of the child's progress. Concentrator use led to increased electricity costs of the household by 15 US dollars per month above normal. This led to caregivers using the backup cylinders more often resulting in higher costs for the program. All caregivers despite counselling wouldn't use the oxygen on a continuous basis as they felt their child would be addicted to oxygen and intermittent use would help to "outgrow their oxygen addiction". Equipment factors: 2(10.5%) of the concentrators used in the fields were portable with battery backups and cost 1500 US $ each and unfortunately 2-3 months after use they broke down and despite costly maintenance were irreparable. One of the concentrators used in the field stopped working after tea and soup was accidentally poured in it whilst being used as a modified table in a single room slum dwelling. Out of 22 pressure regulators needed for the cylinder or its backup 5 (22.7%) were broken by children playing in the same room as the patient as they are quite fragile. All patients lacked pulse oximeters making it difficult for the caregivers to accurately adjust the flow of oxygen hence some children during home visits were using higher flows and others less than was required. The home electricity connection at one patient's home was poor and the patient had to be readmitted to hospital. Environmental factors: There was fear from the authors of the safety of HOT as patients came from slum areas where fire breakouts are quite common and our very first patient experienced this on day 13 whilst on HOT and had to be readmitted for safety concerns. This fire was unrelated to the patient's use of HOT. Access to the slum area for maintenance and cylinder delivery was a challenge and motorbikes were used for cylinder delivery. Locating the residence in the slums and frequent relocation by the patients to a different house was a challenge to the nurse as well as assessing adequate electricity power/accessibility/reliability for which health workers are not trained. In one case separated spouses living in two different slum areas made it difficult for movement of HOT equipment with the child. Change of mobile phone contacts without informing the nurse made it difficult to coordinate home visits. Power blackouts were common in all homes some lasting upto 48 hours which increased usage of backup cylinders and increased costs.

Discussion

All 22 patients requiring HOT reside in slum dwellings with financially constrained circumstances and this program has allowed early hospital discharges and shorter readmissions, as the HOT equipment remained at the patient's residence, whilst allowing caretakers to engage in gainful employment as the child recuperated in a home setting. Almost half of the study population have now been discharged off HOT successfully. The HOT equipment was promptly returned by the caregivers once the child was off oxygen and this allowed us to rapidly assist the next child. The median duration use of HOT was 343 days while in Malaysia, Norzilla et. al. in 2001 had a median of 105 days2.

Our patients had a mean duration of 112 days in hospital waiting for HOT before this program was initiated, currently this has reduced to 20 days.

At KNH patients pay a minimum daily charge of 10 US $ thus each day saved by not being in hospital equates to huge financial savings to both community as well as governmental resources in providing hospital care to its population. It is thus more cost effective to have the patient at home as similarly reported by Bertrand in Chile6.

Home environments allow improvement in sleep and psychological comfort to both caregiver and child the former who at all

times was also expected to remain at the bedside whilst the latter was in hospital. Our HOT allowed one child to walk to a nearby school where for a few hours daily it allowed some educational accomplishment whilst on a portable concentrator. Worldwide HOT programs have shown to reduce morbidity and mortality among children with chronic oxygen need from the disease itself and long hospital stays which exposes them to nosocomial infections. Adde et al from Brazil, in 2013 also reported HOT to be beneficial in preventing pulmonary hypertension which is a common sequela in primary lung disease that leads to cor-pulmonale and increased risks of mortality3. The relatives, neighbours and friends would often assist in care when the parent had to go to work as a majority were casual labourers earning basic minimum wages which in Kenya is 5$ per day.

Three premature babies with bronchopulmonary dysplasia did particularly well on HOT and two were weaned off oxygen and one remains on HOT. These two patients are growing well and have no respiratory complications nor readmissions, hence HOT in Kenya is a feasible program with good outcomes as also seen in Brazil by Garcia et. al.8 In resource rich settings, continuous oximetry is done prior to discharge to HOT as seen from a study done in the United Kingdom in 2019 by Batey et.al. but in our study they were clinically assessed and intermittent pulse oximetry was used several days prior to possible discharge to assess oxygen saturation.9

Minimal target oxygen saturation recommended is ≥ 93% for weaning off HOT using overnight oximetry but this is a challenge in a resource poor setting as seen from our study where no patient was able to afford a pulse oximeter. Hence weaning was relied on by clinical improvement, respirator rates, work of breathing and pulse oximetry done during home review by the nurse or clinic visits with the doctor.There were a number of challenges faced since the start of the donor program. We attempted to fix one battery to an oxygen concentrator for times of no electricity but it added another 5 kilograms to the overall weight and was thus too heavy and not portable. All caregivers feared oxygen addiction and we feel with further education it will improve oxygen compliance. The enrolled children resided in slum areas which are far from the hospital, half of the patients stayed more than 20 kilometers away and one at 100 kilometers distance which made it costly for nursing home and patient clinic visits. Nicholl et al. in the UK showed increased risk of mortality with increased distance from hospital to home and in our study the odds of dying were higher but statistically insignificant.10 Some of the enrolled children resided in either a mud or iron sheet house and hence there was fear of the effects of weather elements such as rain dripping onto the equipment which thankfully did not materialise.

The strength of this study is that it provides a basis for the initiation of public private partnerships to successfully minimise hospital stay in a subset of patients who are at high risk of nosocomial morbidity and mortality. The study shows the challenges faced in providing HOT are not insurmountable even in resource restricted settings.

The main limitation of this study was children who were not enrolled in this study but were discharged on self-funded HOT under the care of private health care practitioners whose outcomes and challenges could not be compared with. Our total number of participants is also small and so statistical analysis is difficult. As this program has grown there is fear of donor lethargy as we anticipate more patients being discharged even earlier and that we will have to increase the number of nurses to provide adequate and timely home visits.

Conclusion

Our program allowed needy children to be discharged earlier with no increase in morbidity or mortality at home. The challenges we faced were not insurmountable and we feel this program can be similarly adopted in other resource restricted settings. Children who require oxygen and their caregivers thrive better in a home environment. There is potential for increased roll out of similar programs worldwide and we hope this article will stimulate others to replicate and improve the same.

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