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Home phototherapy for neonatal jaundice in the UK: a single-centre retrospective service evaluation and parental survey

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ABSTRACT

Background In the UK setting, where neonatal jaundice treatment is required, it is largely carried out in hospitals. However, it is possible to safely administer home phototherapy (HPT).

Objective To report on our centre's experience of HPT and its potential benefits.

Design Retrospective observational study performed as a service evaluation.

Patients Infants ≥35 weeks corrected gestational age with a weight of 2 kg and serum bilirubin ≤50 μmol/L above treatment thresholds. Controls were a matched group of infants who received inpatient phototherapy (IPT). Setting The catchment area of two neonatal intensive care units, one special care unit and a birth centre at four different hospitals that is covered by a single neonatal community outreach nursing team in Birmingham, UK. Intervention HPT was started either in the community or as a continuation of IPT. Controls received IPT. Main outcome measures The rate of bilirubin reduction, hospital readmission rates and parental

Results 100 infants received HPT while 50 received IPT. No infant showed a progressive rise of serum bilirubin level while receiving HPT. The rate of bilirubin reduction was similar in both HPT and IPT groups (2.4 \pm 1.9 and 2.5 \pm 1.6 µmol/L/hour, respectively, MD=-0.1, 95% CI -0.74 to 0.53, p=0.74). Readmission rate was 3% in the HPT group. 97% of parents stated that the overall experience was good and 98% would choose HPT if they had their time all over again.

Conclusion Our programme suggests that HPT for neonatal jaundice can be carried out in a select group of infants. It helps in providing holistic family-centred care and is viewed positively by families.

BACKGROUND

satisfaction.

Jaundice is almost universal in newborn infants and, where treatment is required in the UK setting, it is generally undertaken in hospital. However, it is possible to safely administer home phototherapy (HPT) for jaundice in patients' own homes. This practice has been accepted as an alternative to inpatient phototherapy (IPT) in several

What is known about the subject?

- Inpatient phototherapy is routinely used to treat neonatal jaundice.
- Although home phototherapy is commonly used in other countries such as the USA, it is rarely used in the UK.
- No high-quality evidence is currently available to support or refute the practice of home phototherapy in the UK.

What this study adds?

- Phototherapy can be delivered at home in a select group of infants and could be an ideal option during the COVID-19 pandemic.
- ▶ It can be as effective as inpatient phototherapy, potentially prevent occupancy of acute beds and help in delivering family-centred care.
- ▶ It is well received and positively viewed by parents.

high-income countries such as the USA where it is accepted practice. $^{3\,4}$

HPT helps to prevent prolonged hospitalisation and re-admission. It can promote mother-infant bonding and lead to increased parental satisfaction.⁵ While the existing published studies have focused on the efficacy of HPT, they rarely commented on parents' satisfaction. Patients' experience is an important and commonly used indicator for measuring the quality of service in healthcare. There is increasing evidence that it is positively associated with clinical effectiveness and patient safety.⁶⁷ It is also a measure of patient-centredness, one of the six healthcare quality aims proposed by the Institute of Medicine.⁸ Patient satisfaction affects clinical outcomes, patient retention and is linked to improved compliance with clinician's instructions, timely care seeking, greater comprehension and retention of information.



Our HPT service was set up in 2018 and is now supported by a 7-day neonatal community outreach nursing team (NCOT) and one consultant. We report on our centre's experience of the HPT service and analyse the outcomes for infants treated at home.

METHODS Setting

The Birmingham Heartlands Hospital NCOT covers a large catchment area with around 18000 deliveries per year. The area covers a tertiary neonatal intensive care unit (NICU), special care unit and birth centre in three different hospitals which are part of the University Hospitals Birmingham National Health Service (NHS) Foundation Trust and another NICU at Birmingham Women's Hospital.

Population

We included all infants who received HPT. The eligibility criteria for HPT were infants with corrected gestational age (CGA) \geq 35 weeks, weight \geq 2 kg, \geq 48 hours of age and serum bilirubin (SBR) \leq 50 µmol/L above treatment thresholds according to The National Institute for Health and Care Excellence (NICE) guidelines. Infants in the control group were CGA matched, \geq 48 hours old and received single phototherapy as per hospital policy. To be eligible for HPT, parents needed to be able to converse in English, follow instructions regarding the use of HPT equipment and have a satisfactory home environment. Infants with severe haemolytic jaundice, SBR level >50 µmol/L above treatment thresholds, age of <48 hours and infants whose parents were not conversant in English were ineligible for HPT.

Data were collected retrospectively from infants' medical records over the period from April 2018 to September 2020 for HPT and from January 2019 to September 2020 for IPT. For consistency, the total duration of phototherapy was calculated using the timing of bilirubin level before HPT started to the timing of bilirubin level when HPT stopped.

Intervention

HPT was delivered using a NeoMedLight BiliCocoon Bag system device (figure 1). The irradiance of BiliCocoon was $35 \,\mu\text{W/cm}^2/\text{nm.}^{11}$ IPT was delivered via Dräger



Figure 1 BiliCocoon bag system used for home phototherapy.

Bililux with irradiance of >33.5 μ W/cm²/nm at 50 cm.¹² HPT could be a continuation of IPT or commenced in the community. Infants referred from the community needed initial clinical examination by a clinician in hospital, repeat SBR, conjugated bilirubin, full blood count and direct Coombs test (DCT).

Parents were taught to use the phototherapy equipment, signed written consent for HPT use and received a feedback sheet to complete at the end of treatment. The NCOT visited daily to review infants and perform serum SBR. Once SBR level was ≥50 µmol/L below the treatment threshold, HPT was stopped and a rebound level taken 12–24hours later. If satisfactory, the device and feedback form were collected.

Parental feedback

The feedback form consisted of two types of questions. The initial part sought to determine parental experiences through a series of closed questions. These questions were structured to allow for a 'yes' or 'no' response, with a space provided for additional comments if needed. The second part of feedback sought to discover the personal experiences and opinions of parents about the HPT service through open questions (see online supplemental file 1).

Outcomes

The primary outcome was to report on the effectiveness of HPT, represented by the rate of fall of bilirubin and hospital readmission rates. It was also defined as the avoidance of significant rise of SBR that puts infants at risk of kernicterus or readmission for intensive IPT. Secondary outcomes included parental satisfaction and duration of phototherapy.

Statistical analysis

Data were analysed using GraphPad Prism V.8.4.3 (471). Data were presented as mean±SD for normally distributed continuous data and median and IQR for skewed continuous data. Comparison was performed using the χ^2 test for categorical data and Student's t-test or Mann-Whitney U test for continuous data as appropriate.

Patient and public involvement

Patients or the public were not involved in the design, conduct or reporting of our study.

RESULTS

We included 100 infants in the HPT group and 50 infants as controls. Their characteristics are included in table 1. HPT was initiated in the community in 52 (52%) infants, while 48 (48%) infants received it as a continuation of IPT (table 2). The rate of bilirubin fall was similar in both HPT and IPT groups (mean 2.4±1.9 and 2.5±1.6 µmol/L/hour, respectively, MD=-0.1, 95% CI -0.74 to 0.53, p=0.74) (table 1). No infant showed a progressive rise in SBR level in HPT group.



Table 1 Characteristics, rate of bilirubin fall and duration of phototherapy for infants treated with home phototherapy and control group

	HPT Total	IPT Control	_ P value MD (95% CI)*
	n=100	n=50	
Gestational age in weeks†	37±1.8	37±1.3	0.12‡ -0.43 (-0.99 to 0.12)
Birth weight in g†	3008±617	2897±538	0.84‡ 20 (–182 to 223)
Gender Male	53 (53%)	28 (56%)	0.72§ 3% (-0.1392 to 0.1992)
Age (days) at onset of phototherapy¶	5 (3–6)	5 (3–5)	<0.067**
DCT			
Positive	8 (8%)	3 (6%)	-
Not available	4 (4%)	1 (2%)	
Feeding			
Breast feeding	33 (33%)	15 (30%)	0.71§ 3% (-0.1284 to 0.1884)
Formula	33 (33%)	18 (36%)	0.71 3% (-0.1308 to 0.1908)
Mixed feeding	34 (34%)	17 (34%)	1.0 0% (-0.1608 to 0.1608)
Baseline SBR (µmol/L)	271±50	274±72	0.76 -3 (-22.97 to 16.81)
Rate of SBR fall† (μmol/L/h)	2.4±1.9	2.5±1.6	0.74‡ -0.1 (-0.74 to 0.53)
Other investigations††			
Hb†	192±27	-	-
Platelets†	265±75		
Direct bilirubin†	10±6		
Duration of phototherapy in hours†	43±28	26±9	0.0001‡ 17 (9.2 to 25.5)
Readmissions	3 (3%)	0	

Data were available for FBC in 88 infants (88%) and for direct bilirubin in 57 infants (57%) in HPT group.

The total duration of phototherapy was longer in HPT compared with controls, (mean 43±28 and 26±9 hours respectively, MD=17, 95% CI 9.2 to 25.5, p=0.0001) (table 1). Data on the duration of phototherapy as per the device's timer were available in 66 (66%) infants in HPT group. The total duration of HPT was significantly longer (mean 40±23 hours) than the durations recorded on the BiliCocoon timer (mean 24±10 hours, MD=15.4, 95% CI 9.2 to 21.6, p<0.0001). The mean duration of stay for IPT group was 51±19 hours. Two infants required more than one session of HPT and three (3%) required

readmission. One infant among controls required two sessions of IPT.

Parental experience

Feedback received from 100 families was overwhelmingly positive with 95 (98%) stating that if they had their time all over again, they would still choose HPT rather than IPT, while 2 (2%) preferred IPT (figure 2). Detailed feedback is shown in tables 3 and 4 and figures 2–4).

^{*95%} CI of mean difference (MD).

[†]Mean±SD.

[‡]Unpaired Student's t-test.

[§]χ2 test.

[¶] Median ±IQR.

^{**}Mann-Whitney U test.

^{††}Investigations are not routinely performed on infants receiving IPT, but performed on HPT infants for additional safety.

DCT, direct Coombs test; HPT, home phototherapy; IPT, inpatient phototherapy; SBR, serum bilirubin.

Table 2 Characteristics, rate of bilirubin fall and duration of phototherapy for infants received community-initiated and hospital initiated HPT

	Community-initiated HPT	Hospital-initiated HPT
	n=52	n=48
Gestational age in weeks	37±1.7	37±1.8
Birth weight in g	3008±617	3038±614
Gender Male	28 (54%)	25 (52%)
Age (days) at onset of phototherapy	5 (3–6)	5.5 (3–7)
DCT		
Positive	5 (10%)	3 (6%)
Not available	8%	0
Feeding		
Breast feeding	16 (31%)	17 (35%)
Formula	16 (30%)	17 (35%)
Mixed feeding	20 (38%)	14 (29%)
Rate of SBR fall(µmol/L/hour)	3±1.9	1.9±1.8
Other investigations		
Hb	191±21	194±32
Platelets	274±85	255±64
Direct bilirubin	11±7	10±3
Duration of phototherapy in hours	40±24	47±31
Readmissions	1 (2%)	2 (4%)

DCT, direct Coomb's test; HPT, home phototherapy; IPT, inpatient phototherapy; SBR, serum bilirubin.

DISCUSSION

Few studies have examined the use of HPT. Apart from Chang and Waite, most studies had small sample sizes. Our report adds to the increasing evidence on the effectiveness of HPT.³

The breastfeeding rate in both the HPT and IPT group was similar. In the study of Chang and Waite, breastfeeding rate was much higher at 90%, so breast milk jaundice may have been more prevalent in their population.³

In our HPT group, 8 (8%) were DCT positive; one required two sessions of HPT, none showed signs of haemolysis. Chang and Waite found that although 10%

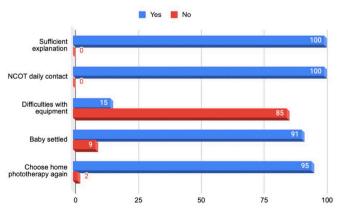


Figure 2 Parental opinions on home phototherapy service. NCOT, neonatal community outreach nursing team.

of their cohort were DCT positive, 5.7% required readmission or another session of HPT.³

The duration of HPT in our cohort was shorter (43 hours) when compared with the reports by Chang and Waite (53 hours) and Thakkar *et al* (57 hours). ^{3 13} When compared with IPT, the duration of HPT was longer. This could be explained by greater parental adherence to treatment due to direct patient supervision and more frequent SBR checks in hospital. This was shown in the

Table 3 Parents' responses to 'what would you say were the main advantages of letting your baby have phototherapy at home?'

Responses	
Total n=100	n (%)
Being in home environment, not having to be in hospital	47 (47)
Family, both parents, other children, family support	44 (44)
Relaxed and settled	26 (26)
Comfort and privacy	16 (16)
Ease, convenience and simple equipment	12 (12)
Maintaining a routine at home	9 (9)
Be with baby at all times, bonding	6 (6)
Carry on with life, freedom	6 (6)



nappies

disadvantages to having phototherapy at home?'				
Responses Total n=100	n (%)			
No disadvantages	82 (82)			
Baby not settling	4 (4)			
Equipment issues and storage	4 (4)			
Having to stay indoors	3 (3)			

Having to stay indoors	3 (3)	
Parent anxiety	2 (2)	
Lack of continuous medical supervision as in hospital	1 (1)	
Difficulties with feeding and changing	1 (1)	

longer total duration of HPT compared with the phototherapy unit timer reading. However, IPT (mean 26±9 hours) was of similar duration to HPT as measured by the device timer (mean 24±10 hours). Our findings agree with Slater and Brewer who reported that the duration of IPT was shorter than HPT.¹⁴ However, Eggert *et al* found that duration of treatment was similar in both IPT and HPT.⁴ On the other hand, Zainab and Adlina reported the duration of HPT was shorter than IPT.¹⁵

Effectiveness and re-admissions

The rate of bilirubin reduction was similar in both HPT and IPT groups. No infant in HPT showed a progressive rise in SBR level. Similarly, the meta-analysis done by Chu *et al* showed that there was no difference in bilirubin reduction rate between HPT and IPT. On the other hand, Zainab and Adlina reported the rate of fall was higher in HPT group compared with controls. However, it is unclear whether the devices used for HPT and IPT delivered the same irradiance. ¹⁵

In our cohort, HPT was successful in the majority of infants with three (3%) readmissions due to concerns over treatment failure and non-compliance. Two infants

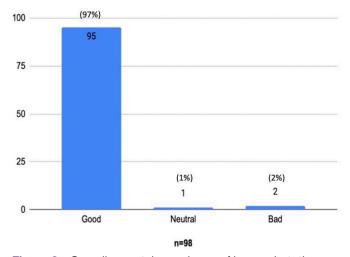


Figure 3 Overall parental experience of home phototherapy service.

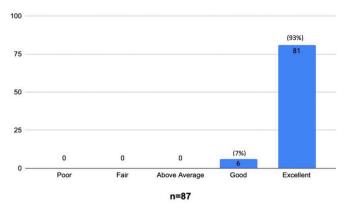


Figure 4 Overall parental rating of home phototherapy service.

required more than one session of HPT; one had suspected Gilbert syndrome. Chang and Waite reported a readmission rate of 1.9%. However, they used different treatment thresholds.³ Reducing readmission rates help NICUs maintain available maternity beds for high-risk intrauterine transfers requiring delivery in tertiary perinatal centres. It also reduces bed occupancy on paediatric wards freeing beds for acutely unwell children.

Parental feedback on HPT

In our cohort, the responses to the initial questions in the questionnaire indicated high levels of satisfaction with the service. All parents agreed that staff had sufficiently explained how to use the equipment, and that the NCOT had contacted them daily until 1 day after phototherapy was stopped. Similarly, Jackson *et al* reported that all parents were highly satisfied that all information concerning the HPT had been supplied to them. ¹⁶ However, they received feedback from only 28 parents.

A minority of parents in our HPT group did experience some difficulties with the equipment, such as struggling to put the eye masks on their infants and the eye masks slipping during treatment. Similarly, a few parents reported the mask causing discomfort to their baby who then needed frequent picking up in order to settle.

In the second part of the questionnaire, when asked about the main advantages of HPT, the two most common themes in the responses were being in the home environment and around their families. A number of parents expressed relief at not having to be in hospital in order to receive phototherapy. Additionally, having support from other family members and spending time with other children was cited as another advantage. Ease and convenience were also common themes, with several parents noting how simple the equipment was to use. A number of parents cited comfort, both for the baby and themselves, as the main advantage. Similarly, in the study by Jackson *et al*, 86% of parents reported that HPT always fitted with their family routine. ¹⁶

For a balanced assessment, parents were also asked to list any disadvantages they had encountered. Eightyfive per cent found no disadvantages with HPT, however,

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some concerns were expressed. The two main disadvantages were equipment issues, with a few parents finding the equipment bulky and difficult to store, as well as the baby not settling in the HPT unit. A few parents found being responsible for their baby's care without constant medical supervision anxiety-inducing, and thus did not feel entirely confident.

It is comforting that 95 (97%) parents stated the overall experience of HPT was good and 95 (98%) reported that they would choose HPT if they had to do it all over again and be advocates for the service to other families. Two parents (2%) stated a preference to IPT in future, having found HPT too stressful. Our team has used the few reported difficulties by some parents especially with the eye masks to forewarn future families along with suggestions as to how this could be overcome which could further reduce the parental anxiety this might produce.

Feasibility

Our results show that infants ≥2 kg and ≥35 weeks CGA can be treated with HPT. Zainab et al included infants ≥37 weeks while Chang and Waite only included infants with SBR levels 34-51 µmol/L below treatment thresholds as per the American Academy of Pediatrics (AAP) guidelines.³ 15 The NICE treatment thresholds are quite different from the AAP thresholds. Whereas NICE guidelines offer gestation-specific thresholds at weekly intervals up to 38 weeks, the AAP guidelines offer a composite guideline for infants ≥35 weeks. Further, AAP guidelines advise against the use of HPT unless the bilirubin levels are 34-51 umol/L below the treatment thresholds. In UK practice, phototherapy is commenced if SBR level is above NICE treatment thresholds. So, we included infants who met that criteria that is, infants who normally need admission to hospital for phototherapy, this means infants included in the Chang et al report would not have met the NICE criteria for treatment. It is also possible to treat carefully selected infants with mild haemolysis with HPT.

Infants in the control group could have been candidates for HPT. However, they were not offered HPT due to either (1) the lack of knowledge of junior doctors about HPT especially at the launch of the service and during change over period of new junior doctors, (2) the lack of availability of trained personnel during out of hours to teach parents how to use equipment, (3) parents did not feel confident to use HPT or (4) parents were not conversant in English.

Resource use

The average length of IPT was 51 hours which equates to 2.1 bed days per infant that could be saved. This potentially saves 204 bed days for 97 HPT infants as three (3%) required readmission. This could help in improving patient flow on maternity wards. While a comprehensive economic analysis was outside the scope of this observational study, baseline data from our hospital and the costing of HPT service demonstrated clearly the efficiency of delivering care in this

manner. The one-off cost of machinery and ongoing costs of home visits have to be weighed against the costs of occupying acute beds and the difficulties mothers experience when away from their families. ¹⁷ In light of the COVID-19 pandemic, we need to find different ways of providing care to keep families together and safe.

Considerations for healthcare professionals

Although HPT is a convenient alternative to IPT, it is not suitable for all infants and families. Infants with very high bilirubin levels may not be eligible for HPT due to the lack of direct supervision in the community and the need for intensive IPT. HPT relies on parental compliance and confidence to use the equipment without constant supervision. This requires clear and effective communication, which may be impeded by failure to employ translators where language differences exist.

We sought the feedback of our service users as user feedback is a powerful developmental tool for any service. Measurements of patient satisfaction using appropriately designed and delivered surveys provide robust measures of the quality of care and can help improve services and their delivery. On the contrary, dissatisfaction with healthcare leads to poor compliance and in extreme cases, patients resorting to negative word-of-mouth reports that discourage others from seeking healthcare from the system. HPT service perfectly complements the recently launched NHS At Home, a drive to give people more personalised, supported and connected care in their own homes which reduces the need for hospital attendances or admissions. On the contrary the service perfectly complements the recently launched NHS at Home, a drive to give people more personalised, supported and connected care in their own homes which reduces the need for hospital attendances or admissions.

Strengths and limitations

To our knowledge, this is the largest cohort of HPT for neonatal jaundice in the UK. Our report not only demonstrates the feasibility of incorporating HPT in UK clinical practice but also is supported by overwhelmingly positive parental experiences.

However, our study is limited by the inherent limitations of retrospective studies. It was not possible to measure the exact duration of HPT. Although the NeoMedLight devices have a timer display which records treatment duration, the data were only available in 66 (66%) cases. The way in which we have measured the duration of HPT likely over-estimated the total duration of HPT. Selection bias may have been introduced in parental feedback because feedback was received from parents who agreed for their infants to received HPT in the first place. However, it is not possible to get feedback about a service from people who did not receive that service.

CONCLUSION

Our report demonstrates that HPT for neonatal jaundice can be administered in a select group of infants and is viewed very positively by families. It enables mothers and their infants to remain at home receiving family support and could reduce occupancy of acute beds. We would,



however, recommend larger prospective studies before adopting the practice across the UK.

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