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ORIGINAL ARTICLE

Ambulatory prostanoid therapy: safe reduction in duration of inpatient training

Sally Reddecliffe *, Adele Dawson, and Gerry J. Coghlan

Pulmonary Hypertension Service, Royal Free London NHS Foundation Trust, LG Floor, Pond Street, London NW3 2QG, UK

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Aims IV prostanoid therapy for advanced pulmonary arterial hypertension requires lifelong, continuous infusion, and extensive self-care. The inpatient training pathway (ITP) ensures patient competency but can be psychologically and physically demanding. Therefore, an alternative Elective Prostanoid Admission Pathway (EPAP) was developed. Compare clinical outcomes and patient experiences for patients following the EPAP vs. the ITP.

Methods and results From 2013, clinically stable patients were trained via the EPAP, which consisted of pre-admission including an outpatient training day, followed by inpatient training. The EPAP patients were followed-up face-to-face/via telephone and could access a Clinical Nurse Specialist-led telephone service between appointments. Very high-risk patients were trained via the ITP, which consisted of pre-therapy counselling and daily ward-based training. Prior to 2013, patients followed the ITP pathway irrespective of clinical status. All were enrolled into the 'IV buddy' scheme and retrospectively asked to complete patient experience surveys. Among EPAP ($n = 24$) and ITP ($n = 54$) patients, 17% and 33% discontinued therapy, respectively. Among all, frequent challenges to treatment initiation were: dexterity (43%) and body image (27%). Elective Prostanoid Admission Pathway use reduced inpatient stay duration by 8 days per patient and infection rates remained low. Patient experience surveys [$n = 17$ (EPAP), $n = 10$ (ITP)] showed equal patient satisfaction between groups, but the incidence of side effects was numerically lower in EPAP patients, who also reported home practice and having access to the 'IV buddy' scheme as 'very useful' [12/14 (86%) and 10/13 (77%), respectively].

Conclusions Elective Prostanoid Admission Pathway implementation improved patient outcomes and has the potential for application to other clinical scenarios where patient self-management is required.

Keywords PAH • Patient self-management • Intravenous • Epoprostenol • Patient experience survey • EPAP

Implications for Practice

- The results of this study unequivocally highlight the benefit of an outpatient training process [elective prostanoid admission pathway (EPAP)] over an inpatient training process [inpatient training pathway (ITP)]. This was true in terms of both clinical and patient-reported outcomes
- Elective prostanoid admission pathway implementation resulted in a better training and treatment experience overall with reduced incidence of side effects, the feeling of being more able to cope with side effects, reduced number of inpatient bed days, and better access to some services (e.g. home practice and the 'IV buddy' scheme)
- The substantial reduction in the number of inpatient bed days following EPAP implementation would have myriad implications for clinical practice, including reduced patient harm (e.g. hospital-acquired infections, falls and fractures, delirium, dependency), reduced pressures on hospital resources, and reduced risk of unwarranted costs
- It is anticipated that learnings from this study will be used to improve the experience of current and future patients with pulmonary arterial hypertension who require IV prostanoid therapy
- Moreover, this method has the potential to benefit a range of clinical scenarios where the efficacy of complex therapy is dependent on the effectiveness of patient self-management

* Corresponding author. Tel: +44 (0)207 4726354, Email: s.reddecliffe@nhs.net

INTRODUCTION

Pulmonary arterial hypertension (PAH) is a chronic, progressive disorder most commonly seen in women involving the obstruction of small pulmonary arteries and increased pulmonary pressure.[1] This pressure increase puts a strain on the right heart, ultimately leading to heart failure and death.[2] Initial symptoms usually appear during physical exertion and can include shortness of breath, weakness and fatigue, and angina.[3] The prevalence and incidence of PAH in Europe (including France, Scotland, Belgium, UK/Ireland, and Spain) are in the range of 6.6–26.0 per million and 1.1 to 7.6 per million/year, respectively.[4–8]

Although treatment strategies have advanced significantly in the last two decades, the mortality rate (15% within 1 year of diagnosis) remains high.[9] This may be partially attributable to the complexity of available treatments. Epoprostenol is a synthetic prostacyclin and a potent vasodilator effective in the treatment of advanced PAH.[3,10] Due to its very short half-life (3–5 min),[3] epoprostenol must be delivered on a continuous basis via a central venous catheter (CVC) with an infusion pump and requires a high degree of patient self-management. Broadly speaking, self-management is defined as the day-to-day management of chronic conditions by individuals over the course of an illness.[11]

Successful treatment with IV epoprostenol is dependent upon the patient being fully competent in managing all aspects of therapy and allowing the pump system to flow continuously without interruption. This is particularly important given that guidelines state abrupt interruption should be avoided, because in some patients this may lead to PH rebound with symptomatic deterioration and even death.[3] Serious adverse events (SAEs) related to the CVC delivery system include pump malfunction, infection, catheter obstruction, and sepsis.

Taken together, clearly there are many possible challenges associated with IV epoprostenol therapy and it is crucial that patients are fully trained and competent before being discharged on treatment. The current standard inpatient training pathway (ITP) used across most National Health Service (NHS) trusts for initiation of ambulatory prostanoid therapy is labour intensive, slow (average 14 days as an inpatient but can take up to 3 weeks), and stressful for patients (steep learning curve, limited family involvement in the process). Patients trained via the ITP will have had time to discuss their concerns with an assigned 'IV buddy' patient if deemed clinically stable enough and will receive some limited exposure to educational material in both video and literature form. However, ITP patients have very restricted hands-on experience of physically managing the equipment before admission. They must learn all the practical aspects of managing the system and develop confidence in self-management while in an alien environment, often under high stress and with limited access to one family member at most. Patients trained via the ITP are usually a very long way from home due to the need for admission to a specialist centre and will receive 3–4 h of direct nurse specialist support per day while learning. This prolonged hospital stay is often associated with limited opportunities for exercise, greater exposure to hospital infections, and social isolation leading to a deterioration in wellbeing. The patient is also deprived of their independence at a time when they are trying to increase self-reliance while learning an alien technique. For patients (as well as carers and hospital staff), the entire process can be physically demanding and psychologically intensive. Therefore, we sought to develop an alternative training protocol that limits the above negative impacts of the standard ITP. Here, we describe a novel training and treatment programme termed the Elective Prostanoid Admission Pathway (EPAP) which was developed at the Royal Free Hospital, London to address these challenges and ultimately improve the experience of patients and carers.

The aims of this study were to:

- Directly compare the EPAP with the conventional ITP
- Assess patient and clinical outcomes following implementation of either the EPAP or the ITP
- Gather retrospective patient experience data on each of the two training pathways, with the ultimate goal of improving patient experience outcomes overall

METHODS

EPAP development and implementation

The rationale for the development of the EPAP is shown in *Table 1*.

The EPAP consisted of three stages (described below) specifically designed to help patients gain full competency in self-managing their treatment prior to discharge (*Figure 1*). The EPAP was the preferred training pathway for all; however, only patients deemed sufficiently clinically stable to be partially trained in the outpatient setting were able to be assigned to the EPAP training group, with the remainder following the ITP.

Stage 1: Pre-admission process

During pre-admission, patients and carers were seen in the clinic by the pulmonary hypertension (PH) team who provided pre-therapy counselling and a range of written information. During this stage, the Clinical Nurse Specialist (CNS) team facilitated practical demonstrations including how to use the equipment (e.g. CVC and pumps) and how to maintain aseptic conditions. At this point in the process, patients were asked to enrol into the 'IV buddy' scheme, allowing them to contact a fellow patient as part of their support network. After these initial discussions, if the patient was happy to continue with therapy, suitable appointment dates for the outpatient training day, admission for inpatient training, and line insertion were agreed at this stage. This was done in advance to allow patients, family members and carers to prepare, both psychologically and logistically.

Table 1. Rationale behind development of the EPAP

The EPAP was designed with an incentive to:
• Reduce the number of patient bed days required
• Improve patient/carer confidence and satisfaction with the training process
• Formalise the process of CVC insertion
• Identify possible patient training failures prior to admission
• Utilise the CNS team's time more effectively
• Reduce travel costs and the demands on patient's/carer's time
• Reduce infection rates

CNS, Clinical Nurse Specialist; CVC, central venous catheter.

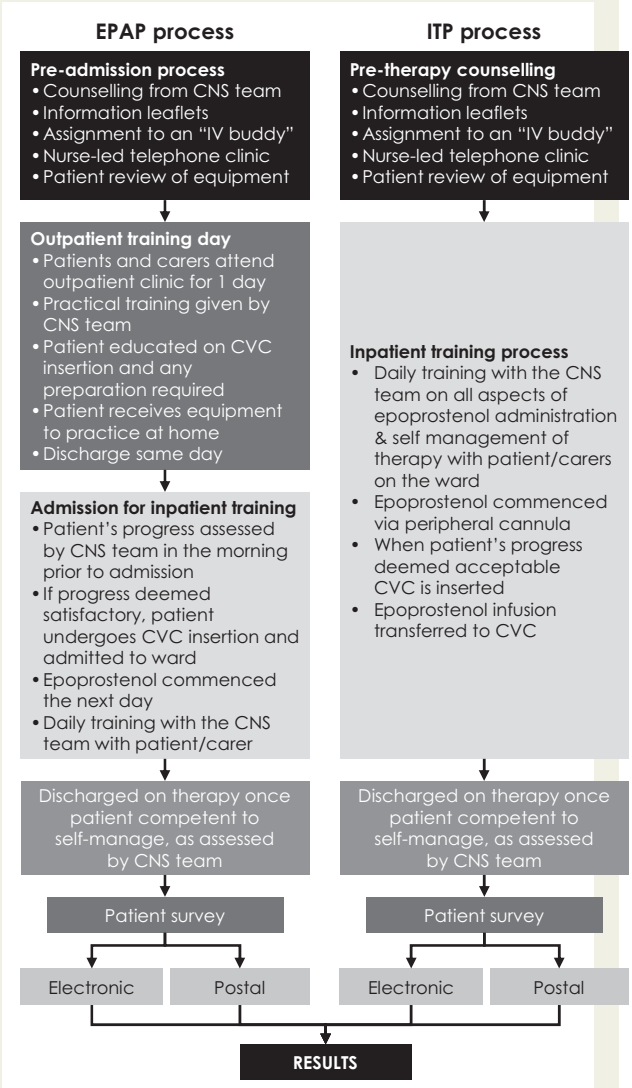

Figure 1. Schematic of the training procedures and patient survey process. CNS; Clinical Nurse Specialist; EPAP, Elective Prostanoid Admission Pathway; IV, intravenous.

Stage 2: Outpatient training day

Following the pre-admission process, patients and carers were invited to attend a 1-2-1 outpatient training day (1000–1600 h) to begin learning practical skills, including drug reconstitution, pump programming, and aseptic technique. Patients were also prepared for CVC insertion during this time using written information, verbal engagement with the CNS team, and demonstrations using models. Patients left the outpatient clinic later the same day with a supply of equipment and demo pumps for use at home to continue independent practise. Patients continued to access the CNS telephone service during this period of home practise.

Stage 3: Admission for line insertion and inpatient training

At 1000 h on the day of admission, the patient's level of competency and willingness to continue with therapy was determined by the CNS team in the outpatient clinic (Supplementary material online, *Table S1* details how competency was assessed in both groups). Patients deemed not competent to proceed with further training or those not willing to continue, were advised on an alternative care plan and discharged home. Patients deemed competent to proceed with further training underwent elective CVC insertion at 1400 h the same day and received their first dose of IV epoprostenol therapy the following morning. As a general guide, patients received an initial dose of 2 ng/kg/min which was then increased by 1 ng/kg/min each day or as tolerated. However, exact dosing schedules were individualized for each patient as per the guidance of the clinical team. Following treatment initiation, the CNS-led inpatient training phase of the EPAP was tailored to individual needs and aimed to provide patients with daily training until they were able to cope with all aspects of self-management ready for discharge. Post-discharge, follow-up was carried out via face-to-face and telephone clinics, with patients also having access to CNS-led telephone service for advice and support between appointments.

ITP comparator group

Our aim was to train all patients via the EPAP where possible. However, patients with PAH who were acutely unwell (e.g. in overt right heart failure), or those deemed to lack the capacity to learn at a distance prior to IV epoprostenol therapy initiation, were trained in the inpatient setting. A separate population of patients ($n = 54$) who had undergone inpatient training from 2004 with the same CNS team were identified for comparative purposes and termed the ITP group. *Figure 1* details the process of the ITP in direct comparison with the EPAP. The main difference between the two training procedures was that the most clinically unstable patients trained via the ITP were admitted to hospital for the entire training period, as opposed to the more clinically stable patients who were trained via the EPAP partially in the outpatient setting before being admitted for CVC insertion, epoprostenol initiation, and completion of self-management training. One further difference was access to the 'IV buddy' service. Patients deemed significantly clinically unstable were not assigned an 'IV buddy' due to the potential negative psychological impact this may have on the assigned buddy. Inpatient training pathway patients had equal access to a CNS-led telephone service for advice and support between appointments.

Measurement of baseline characteristics

To form a standard assessment of PAH severity, baseline characteristics including World Health Organization functional class (WHO FC), 6-minute walk distance (6MWD), N-terminal pro-B-type natriuretic peptide (NT-proBNP) levels, right atrial pressure (RAP), mean pulmonary artery pressure (mPAP), pulmonary vascular resistance (PVR), and cardiac index (CI) were measured immediately prior to initiation of IV epoprostenol therapy. Patient risk profile at the time of initiation of IV therapy was assessed using the European Society of Cardiology (ESC) risk scoring system as suggested by Kylhammer *et al.*[12]

Line insertion and management of suspected infections

Following IV antibiotic administration (typically teicoplanin over 30 min), CVC insertion was performed under full sterile conditions. C-

reactive protein (CRP) was monitored daily for the following week and patients were advised to contact the CNS team via the 24 h help line in the event of pyrexia or flu-like symptoms. At each follow-up (telephone or face to face) signs of infection were assessed. Infection was suspected where unexplained pyrexia, flu-like symptoms, worsening breathlessness, or CRP elevation was identified. Patients with suspected line infection were admitted for investigations including blood tests to assess full blood count (FBC), CRP levels, and peripheral blood cultures and unless an adequate cause for symptoms was found, the CVC was removed within 48 h of admission and the line tip swabbed. The CVC was also removed in instances of a local exit wound infection that was unresponsive to simple measures. A new CVC was inserted when infection was either excluded or resolved. Only those with positive blood cultures or line tip cultures were considered to have sepsis.

Patient experience survey

Patients trained for IV epoprostenol therapy via either the EPAP (2013–17) or ITP (2004–16) were asked to complete anonymous surveys retrospectively to assess the patient experience. Patients who were subsequently trained via the EPAP but not included in the initial evaluation (2017–18) were also sent evaluation surveys. The surveys included both qualitative and quantitative questions using a Likert scale to allow for direct comparison between the two training groups. Depending on patient preference, patients were invited to complete a survey relevant to their training experience either online via Survey Monkey or via postal service. Full details of the questions asked are provided in the Supplementary material online *Tables S2* and *S3*.

Data collection

All patients under the care of the National Pulmonary Hypertension service have their clinical, investigational, and admission data entered prospectively into the local pulmonary hypertension database and uploaded at 3-monthly intervals to NHS digital. Patient therapy, dose, and all ambulatory therapy-associated complications are required data fields. Data were collected as per standard procedure for NHS quality dashboard and NHSE service standards. Data collection for the patient experience surveys was in line with NHSE service standards and trust policy on patient engagement. Data of relevance to the study but not mandated for the national database (e.g. duration of admission) were retrospectively entered after a full notes review.

Reporting guidelines

The Standards for QUality Improvement Reporting Excellence (SQUIRE) guidelines were used in the preparation of this manuscript.[13]

Ethics and consent

Data were collected prospectively as part of the national audit programme and analysed retrospectively. The investigation conforms to the principles outlined in the declaration of Helsinki. Retrospective patient experience surveys were sent and received anonymously with patients making their own informed decision about whether to respond or not.

RESULTS

Patients, demographics, and baseline characteristics

Between 2004 and 2017, 24 and 54 patients initiated IV epoprostenol therapy after being trained via either the EPAP or ITP, respectively. *Figure 2* shows the various stages of patient recruitment and the number of patients in each cohort. Patient demographics and disease characteristics are shown in *Table 2*.

Patient outcomes

In the EPAP group, patients were trained and began therapy between July 2013 and February 2017 whilst, in the ITP group, patients were trained and began therapy between March 2004 and February 2016. Patient outcome measures for both the EPAP and ITP groups are shown in *Table 3*.

Discontinuation

In the EPAP ($n = 24$) and ITP ($n = 54$) groups, the treatment discontinuation rates (excluding discontinuation due to death) were 17% and 33%, respectively. Reasons for discontinuation, in the EPAP and ITP groups, respectively, were death due to PAH [$n = 8$ (61%) and $n = 28$ (87%)], death unrelated to PAH [$n = 1$ (4%) and $n = 4$ (7%)], death due to mixed/unclear causes [$n = 4$ (17%) and $n = 0$], efficacy failure [$n = 2$ (8%) and $n = 7$ (13%)], patient choice/perceived lack of benefit [$n = 0$ and $n = 5$ (9%)], and clinical decision [$n = 2$ (8%) and $n = 7$ (13%)]. Patients who later received alternative diagnoses of pulmonary veno-occlusive disease were included in the efficacy failure data. Reasons for clinical decision to discontinue were side effects, patient's inability to safely self-manage therapy, symptom improvement enabling management with oral therapies, and therapy stopped on day of transplantation.

In the ITP group, the mean (SD) duration of therapy was 292 days (±371) or 0.8 (±1.0) years for the 18 patients who discontinued therapy (*Table 3*). However, this result was skewed by a patient who received treatment for 3.6 years before very abruptly self-stopping at home due to sudden perceived lack of benefit, with the remaining 17 patients discontinuing after 231 days (± 274) or 0.6 (± 0.8) years of therapy. In the EPAP group, the mean (SD) duration of therapy before cessation was 151 (± 65) days or 0.4 (± 0.2) years. At data cut-off (15 August 2018), 8/24 patients (33%) in the EPAP group and 8/54 patients (15%) in the ITP group remained on therapy.

Infection

Overall, the adoption of the EPAP training process was associated with very low rates of infection. Over the 5-year analysis period, one patient acquired a line sepsis, as defined by a positive blood culture, and one a suspected infection, corresponding to an infection rate of one in 9066 line days (CVC in place) or one infection in every 25 years, in both instances. By comparison, the infection rate in the ITP group ($n = 55$ for this comparison, *Figure 3*) was 1 in 10 473 line days or 1 infection in every 29 years, while the corresponding figures for suspected infections were 1 in 2464 line days or approximately 1 every 7 years. While the data do not permit statistical analysis, the rate of positive blood cultures (confirmed infection) appeared similar for the two patient groups, while the rate of suspected infections appears higher in the ITP group (*Figure 3*).

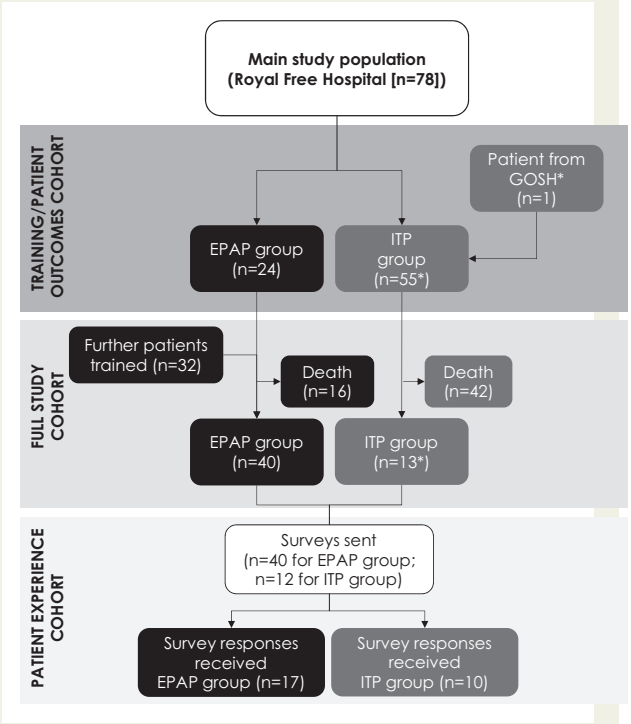

Figure 2. Patient recruitment schema. Schematic showing the various stages of patient recruitment. Note that patient recruitment into the EPAP group was continuous during the study period. All patients assigned to either the EPAP or ITP groups followed the same respective training process, regardless of when they were recruited. The training/patient outcomes cohort included 24 EPAP and 55* ITP patients who were included in the first part of the study, which assessed patient and clinical outcomes and infection rates. Patients who were recruited and trained via the EPAP after this assessment point (2017–18; $n = 32$) were included in the full study cohort and sent retrospective surveys to assess their training experience only; clinical outcomes for these patients were not assessed in this study. *Infection rate data included one patient in the ITP group who initially trained at GOSH. The patient later came under the care of The Royal Free Hospital and was trained in aseptic technique and infection avoidance. EPAP, elective prostanoid admission pathway; GOSH, Great Ormond Street Hospital; ITP, inpatient training pathway.

Table 2. Patient demographics and disease characteristics

Characteristic	EPAP group ($n = 24$)	ITP group ($n = 54$)
Female, *n* (%)	19 (79)	41 (76)
Age range (years)	34–75	16–79
Mean age (±SD) (years)	57 (±9.7)	53 (±15)
PAH-CTD, *n* (%)	19 (79)	32 (59)
IPAH, *n* (%)	1 (4)	14 (26)
PAH due to other causes	4 (17)	8 (15)
WHO FC, *n* (%)		
III	19 (79)	41 (76)
IV	5 (21)	13 (24)
Mean 6MWD (±SD), m	251 (±134)	219 (±128)
Mean NT-proBNP (± SD) (pg/mL)[a]	3497.4 (±3081.2)	2506.0 (±2201.2)
Mean RAP (± SD) (mmHg)[b]	10.9 (±4.6)	12.3 (±5.0)
Mean mPAP (± SD) (mmHg)[a]	52.7 (±8.4)	55.8 (±11.9)
Mean PVR (± SD) (dynes/s/cm^{-5})[c]	739.6 (±237.5)	921.6 (±375.2)
Mean CI (± SD) (L/min/m^2)[d]	2.7 (±0.8)[a]	2.4 (±0.8)
Mean ESC score from routinely collected parameters (±SD)	2.3 (2–3)	2.4 (2–3)

[a]Data from only 53 patients in the ITP group.
[b]Data from only 51 patients in the ITP group.
[c]Data from only 48 patients in the ITP group.
[d]Data from only 16 and 45 patients in the EPAP and ITP groups, respectively.
6MWD, 6-minute walk distance; CI, cardiac index; EPAP, elective prostanoid admission pathway; ESC, European Society of Cardiology; IPAH, idiopathic pulmonary arterial hypertension; ITP, inpatient training pathway; mPAP, mean pulmonary artery pressure; NT-proBNP, N-terminal pro B-type natriuretic peptide; PAH, pulmonary arterial hypertension; PAH-CTD, PAH associated with connective tissue disease; PVR, pulmonary vascular resistance; RAP, right atrial pressure; SD, standard deviation; WHO FC, World Health Organization functional class.

Challenges to therapy implementation and continuation

Many patients experienced more than one challenge. The most common patient-reported challenges among all patients ($n = 78$) were dexterity issues due to underlying connective tissue disease [CTD ($n = 34$; 43%)], altered body image (related to CVC lines and pump; $n = 21$; 27%), lack of family support ($n = 20$; 26%), and lack of confidence/anxiety about treatment ($n = 8$; 10%). Other challenges included comorbid clinical anxiety and depression ($n = 8$, 10%), communication and engagement difficulties ($n = 6$, 8%), living remotely from the specialist centre ($n = 6$, 8%), and concerns around employment ($n = 4$, 5%).

Patient experience survey

Up to 2 years subsequently, retrospective patient experience surveys were sent to all living patients who initiated either training pathway, regardless of completion or therapy status at the time the survey was prepared. See *Figure 2* for further clarification. In total, 40 surveys were sent to patients assigned to the EPAP group (23 via e-mail and 17 via postal service) and 12 to patients assigned to the ITP group (10 via e-mail and 2 via postal service). The survey response rate was 17/40 (43%) for the EPAP group and 10/12 (83%) for the ITP group.

In the EPAP and ITP groups respectively, 86% and 89% of patients were reportedly still receiving IV epoprostenol therapy at the data cut off (15 August 2018). In the EPAP group, patients found being provided with a supply of materials and pump to practise at home very useful (86%), a much higher proportion of

Table 3. Patient outcome measures for EPAP group vs. ITP group at data cut-off

Outcome measure	EPAP group ($n = 24$)	ITP group ($n = 54$)
Inpatient stay duration (days)	6[a]	14[b]
Deaths on treatment, *n* (%)	13 (54)	32 (59)
• PAH-related as a proportion of deaths on treatment, *n* (%)	8 (61)	28 (87)
• Non-PAH-related as a proportion of deaths on treatment, *n* (%)	1 (8)	4 (13)
• Mixed causes/cause unclear, *n* (% of deaths on treatment)	4 (31)	0 (0)
Deaths after discontinuation, *n* (%)	3 (13)	10 (19)
Treatment discontinuation rate, *n* (%)	4 (17)	18 (33)
Duration of therapy for patients who discontinued therapy, mean (SD)	151 (±65) days OR 0.4 (±0.2) years	292 (±371) days OR 0.8 (±1.0) years[c]

[a]$n = 18$; five patients were excluded from the calculation due to prolonged inpatient stays (three due to clinical reasons unrelated to training needs, two due to delay in feasible travel back to Northern Ireland) and one patient's inpatient stay duration could not be retrieved from trust records.
[b]$n = 50$; four patients were excluded from the calculation [one with an extended hospital stay of 66 days for reasons unrelated to PAH, three who transitioned from subcutaneous treprostinil treatment and required minimal inpatient training (between 3 and 8 days only)].
[c]Includes one patient who underwent treatment for 3.6 years.
EPAP, elective prostanoid admission pathway; ITP, inpatient training pathway; NR, not reported; PAH, pulmonary arterial hypertension; SD, standard deviation.

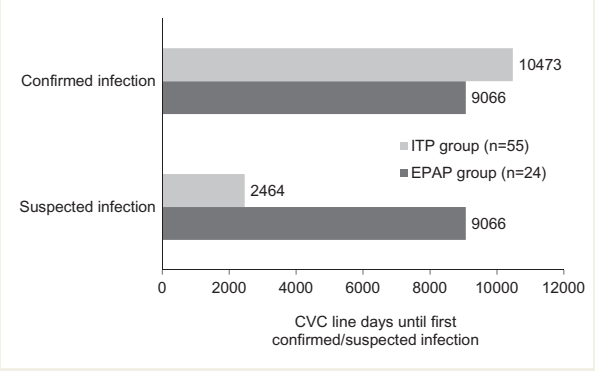

Figure 3. Comparative rates of confirmed and suspected CVC-related bacterial infection in the EPAP group vs. the ITP group. *Note that infection rate data include one patient in the ITP group who initially trained at Great Ormond Street Hospital. The patient later came under the care of The Royal Free Hospital and was trained in aseptic technique and infection avoidance. CVC, central venous catheter; EPAP, elective prostanoid admission pathway; ITP, inpatient training pathway.

patients were able to access the 'IV buddy' scheme (77%) compared with the ITP group (18%) and among these, the service was rated as very useful (77% vs. 100% in the EPAP and ITP groups, respectively). Overall satisfaction with training and treatment was similar between the two groups (87% in the EPAP group vs. 89% in the ITP group said they were 'very satisfied'). Other key data and learnings obtained from the patient experience surveys are shown in *Tables 4* and *5*.

DISCUSSION

The advent of PAH-specific therapies has seen significant improvements in overall prognosis for this severely life-limiting disease.[14] However, this advancement has been accompanied by the need to fully engage both patients and carers in the treatment process due to the demands of self-management.[15]

In this study, we demonstrated that the use of a structured pathway (EPAP) for patients initiating long-term prostanoid therapy via a CVC allowed the patient to be trained partially as an outpatient, which had the two-fold effect of reducing the duration of inpatient stays whilst improving patient outcomes. This novel training method has the potential to benefit a range of clinical scenarios where the efficacy of complex therapy is dependent upon the effectiveness of a patient self-management. Indeed, it is known that the long-term outcomes for patients using PAH-treatment are much improved when the patient is fully engaged with their treatment.[15,16]

Overall, adoption of the EPAP was associated with relatively low rates of premature treatment discontinuation as well as very low rates of CVC-related infection. In fact, cessation and suspected infection rates were numerically lower in patients following the EPAP compared to those observed previously in the ITP group potentially translating to better treatment experience overall. Moreover, lower infection rates are likely related to the patient being more able to maintain aseptic conditions, which could reflect the training environment and the ability to prepare the home environment in advance.

The successful administration of IV prostanoid therapy is dependent upon the ability of patients to manage and comply with the complex delivery systems to ensure safety.[17] Among the EPAP group, we identified a number of physical and psychological patient-reported challenges including dexterity issues, concerns around altered body image, and mental health comorbidities, among others. These findings suggest it may be possible to identify patients who are unlikely to be able to self-manage IV prostanoid therapy or patients who may require additional support prior to treatment initiation to enable a more successful treatment experience.

To further analyse the effectiveness of the EPAP, we asked patients from both groups to complete an experience survey. Based on this, the EPAP yielded a training and treatment experience that overall was equally satisfactory to the conventional ITP. One of the key differences identified

Table 4. Feedback obtained from patient experience surveys

Question	EPAP ($N = 17^a$) *n*/*N* (%)	zITP ($N = 10^a$) *n*/*N* (%)
Did you make use of the 'IV buddy' scheme?		
Yes	13/17 (77)	3/10 (18)
No	4/17 (24)	7/10 (41)
How useful was it to have a fellow patient to talk to about their personal experience of managing therapy?		
Very useful	10/13 (77)	3/3 (100)
How useful did you find being given a supply of materials and pumps to practice with at home?		
Very useful	12/14 (86)	NA
Did you experience any side effects on treatment?		
Yes	10/13 (77)	9/10 (90)
No	3/13 (23)	1/10 (10)
How useful was the training and information provided in telling you about possible side effects of treatment?		
Very useful	11/15 (73)	5/10 (50)
Overall, how well do you feel you coped with the side effects experienced on treatment?		
Very well	9/15 (60)	4/10 (40)
Did you access the CNS-led telephone or e-mail service for advice and support between appointments?		
Yes	13/15 (87)	10/10 (100)
No	2/15 (13)	0
How satisfied were you overall with your training and treatment experience?		
Very satisfied	13/15 (87)	8/9 (89)

[a]Note that not all patients answered all questions, so *N* may vary between questions.
CNS, Clinical Nurse Specialist; IV, intravenous.

Table 5. Key learnings based on responses from patient experience surveys

Key learnings:

- Being offered an 'IV buddy' offers a great level of support and reassurance
- Patients initiating therapy in an emergency situation are not in a position to access the 'IV buddy' scheme due to the severity of their illness
- Being able to practise with real-life demo equipment is helpful, both in hospital and at home
- Troubleshooting training which covers how to deal with technical difficulties such as pump malfunction is pivotal
- Video demonstrations would be a welcome addition to the training programme
- More upfront information regarding both the positives and negatives of treatment may allow patients to continue with epoprostenol therapy
- Fewer side effects were experienced by patients training via the EPAP
- In addition, the EPAP training model was highly effective at preparing patients for side effects and advising patients how to manage these

between the two training types was a lack of uptake to the 'IV buddy' scheme in the ITP group. However, for patients with PAH who are admitted in an emergency, it is often not appropriate for them to access the scheme due to their clinical instability and the need to minimize the psychological impact on the buddy themselves, therefore the risk–benefit ratio must be assessed on an individual basis. Although unavoidable, this disadvantage may be detrimental to the success of prostanoid therapy in patients trained via the ITP as most patients who accessed the scheme rated it as very useful and around a third of patients in the EPAP group lacked family support. Furthermore, those trained via the EPAP reported experiencing numerically fewer side effects and felt more prepared to cope with them when they occurred, which may reflect the delivery of training in a relaxed environment that is more conducive to learning.

Nursing practice has always evolved with the available evidence, wherever possible. As new evidence is released, most recently EPIC 2 and 3 national guidelines on preventing healthcare-associated infections,[18] slight changes in practice have arisen, including the use of novel cleansing and dressing products. Such changes are likely to positively impact infection rates across both the EPAP and ITP groups.

The methods described here have the potential to benefit a range of clinical situations in which patients are required to self-manage complex therapies and the success and efficiency of the EPAP are

being monitored on an ongoing basis within our institution. While its economic benefit is hard to prove, we believe that the reduced number of patient bed days and overall 'very satisfactory' patient experience following the EPAP will translate into more efficient use of NHS resources. Based on this, we believe the EPAP is an equally effective and likely cost-effective alternative to the ITP but the latter will need to be confirmed through further investigation.

Study limitations

- Although the EPAP was delivered as initially intended, and the main aims of reducing patient bed days and improving patient experiences were achieved, it was not possible to formally measure intervention fidelity. Some patients from both groups failed to reach competency following training and therefore did not progress to treatment initiation. However, there are no data available showing the frequency of failures in each group
- Within this study protocol, it was not possible to directly assess any additional or unanticipated effects of the EPAP training process. For example, due to the EPAP being a more relaxed training process undertaken by patients deemed clinically more stable compared with those who underwent the ITP, it could be that patients in the EPAP group were subjected to less stress during training. Moreover, there were no data available showing the time between offer of IV treatment and admission for line insertion. This relies mainly on the availability of an inpatient bed and capacity for labour-intensive training, meaning that, in theory, any delays would be similar for both EPAP and ITP patients. However, the lack of data that prove this is a study limitation. As part of any future studies, it will be valuable to assess the effect of stress or training duration (either at the time of training or retrospectively through patient experience surveys) on patient outcomes
- Data presented for the ITP group are largely retrospective and therefore incomplete, in particular, we were unable to identify training failures (patients admitted for training but who found the system too complex to manage). The response rate to the patient experience survey was poor, as this was an anonymous survey we were unable to undertake further efforts to improve the response rate, and were unable to correlate the responses with clinical features other than training group
- Finally, this study was unable to determine the cost-effectiveness of the EPAP versus the ITP, and it would be beneficial to measure this in future studies. However, it is important to note that all patients were trained by the same CNS team regardless of the training method, meaning no additional staff resourcing costs were incurred. The only additional cost of the EPAP was the allocation of training equipment to practise with at home. This was provided by a clinical homecare pharmacy service, meaning it was not possible to calculate this cost. However, it is assumed that the savings made for the Trust by the vast reduction in patient bed days for those following the EPAP would far outweigh any small additional equipment costs. Despite this data documenting superior outcomes associated with EPAP, cost-analysis would provide a broader perspective of how this intervention may be implemented from a system standpoint

In summary, use of the EPAP reduced the number of patient bed days required without adversely affecting infection rates, was associated with a trend toward a reduced incidence of side effects, and highlighted possible patient training challenges prior to admission whilst at the same time maintaining patient satisfaction with the training and treatment process overall. It is anticipated that learnings from this study, particularly the results of the patient experience surveys, will be used to improve the experience of current and future patients with PAH who require IV prostanoid therapy.

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