

A Journey to a Change in Practice for a Pulmonary Hypertension Care Center

Sarah J Miranda* and Michael L Scharf

Divison of Pulmonary and Critical Care Medicine, Thomas Jefferson University, Philadelphia, United States

***Corresponding Author:** Sarah Miranda, Divison of Pulmonary and Critical Care Medicine, Jane and Leonard Korman Respiratory Institute-Jefferson Health and National Jewish Health, Thomas Jefferson University, Philadelphia, United States.

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Abstract

Purpose: To implement a new nursing position in a pulmonary practice as a specialized nurse coordinator for pulmonary hypertension (PH) patients using a nursing model and current recommended guidelines.

Background: Multiple studies have demonstrated the necessity of specialized care coordination for the pulmonary hypertension population. A pulmonary practice in the city of Philadelphia in need of change manages approximately 125 existing and new PAH patients annually often having multiple complex secondary comorbidities such as HIV, liver disease and/or connective tissue diseases such as Scleroderma. This practice lacks specialized care from a PAH navigator/coordinator. Issues were discovered within the structure of the practice. Patients became frustrated with lack of personalized care and began leaving and seeking care elsewhere. Close management of these patients requires an expertly trained team that specialize in PAH in an Pulmonary Hypertension Care Center (PHCC).

Methods: Change in practice was structured surrounding the principles of Kurt Lewin's nursing framework model called The Change Theory and guidelines by the American College of CHEST physician's panel.

Results: Patients' feedback of their care via Press Ganey scores and verbal report has lead to patient retention and reduced readmission rates. Specifically, patients report that they are extremely happy to have a go-to person for all pulmonary hypertension related needs. From a financial perspective, the PAH physician can see more patients in the office which will increase value-based reimbursement. Finally, the PAH Program Physician Specialist was able to grow and develop the PAH team by providing leadership, education and direction which trickled down to the care coordinator and support staff.

Conclusion: The Pulmonary Hypertension care coordinator is crucial to the growth and maintenance of a specialized comprehensive care center because the nurse navigator acts as a link between the patient, local physicians, specialty pharmacies and the provider. An PH specialty care center equipped with a nurse navigator is imperative for standardizing evidence-based practice for improving patient outcomes.

Keywords: *Care Coordination; Nursing; Pulmonary Hypertension; Advocate; Pharmacy; Insurance*

Introduction

Pulmonary Arterial Hypertension (PAH) is a relatively uncommon disease characterized by such symptoms as exertional dyspnea, fatigue, lightheadedness and syncope that may lead to disability and death. The annual incidence of the idiopathic form of PAH (IPAH) is 1 - 2 cases per million people in the US and Europe. The estimated prevalence of all forms of PAH ranges 10 to 52 cases per million [1]. The mean age at diagnosis has been reported as early as age 36 [2]. PAH requires a right heart catheterization for diagnosis and is defined hemodynamically as a resting mean pulmonary arterial pressure ≥ 25 mmHg, a pulmonary arterial occlusion pressure or "wedge" pressure ≤ 15 mmHg and peripheral vascular resistance > 3 Woods Units [3].

Once considered a rapidly progressive disease, PAH is now a manageable condition that may be treated effectively with one or more medications alone or in combination [4-6]. Despite these medical advances, the median time from onset of symptoms to diagnosis is still too long (> 1 year). The REVEAL Registry found that one in five patients enrolled waited 2 years between the onset of symptoms attributable to PAH and diagnosis of PAH [7-9]. Failure to follow algorithmic guidelines may cause many patients to be shunted between multiple clinicians before receiving a diagnosis [1]. This may delay clinical presentation and thereby, increase mortality. As PAH patients live longer, unique management issues arise such as transitioning medical therapy between intravenous/subcutaneous, inhaled and oral routes which requires a team of clinicians, a care coordinator and support staff expert in PAH [10,11].

About the Practice

Our university-based pulmonary medicine practice manages approximately 125 - 150 existing and new PAH patients and evaluates more than 200 patients with secondary causes of pulmonary hypertension (PH) annually. Many have complex comorbidities such as HIV, advanced liver disease with portal hypertension and/or connective tissue diseases. Though the practice has a physician director (MLS) invested in the PH practice and many, if not all of the important features proposed by the Pulmonary Hypertension Association (PHA) as necessary for a PH care center, the practice lacked a dedicated pulmonary hypertension care coordinator [12,13].

The significance of this deficiency was discovered in the organization of the outpatient practice, where calls are received by certified medical assistants and routed to the PH Program director or were routed to the physician treating PH in an individual patient. The medical assistants did not have the medical expertise to answer patients' queries and therefore, the responses to the PH patients' questions could not always be answered efficiently. Identifying a need for change in the practice surfaced when patients became frustrated with the inefficient communication and began to seek care elsewhere.

Kroening, *et al.* studied whether patient complaints could be linked to high-level patient safety incidents and aimed to determine if any complaints contained information that if acted upon earlier, could have prevented these untoward incidents [14]. Themes of patient complaints included standard of care, treatment delays and failure to coordinate care. Themes of high level incidents included failure to escalate care, communication issues and medication errors. Delay in treatment was shown to be directly related to failure to coordinate care. Their conclusion - listening to patient complaints could reduce risk of medical harm by addressing the issues before they worsen or occur [14].

Pulmonary Hypertension Care Center

An effective PHCC (Pulmonary Hypertension Care Center) as designated by the PHA consists of a PH program physician director, other medical providers, PH nurse, PH program coordinator, pharmacist, social worker, research staff and support staff [13]. A PH care coordinator is commonly a registered nurse or a nurse practitioner, but can also be a physician assistant, respiratory therapist or pharmacist [13]. Stewart, *et al.* elucidates that the PH nurse may or may not be the PH program coordinator. However, the role of the PH nurse in daily patient management includes care coordination, assessment and intervention, education and research, and patient advocacy [15].

PH has varying stages of disease. Advanced stage PH may be accompanied by right-sided heart failure. Major contributing factors to heart failure exacerbations include insufficient knowledge related to changing symptoms and poor patient compliance with the prescribed regimen, specifically diet, medication titration/doing, and weight monitoring [16]. A specially trained nurse coordinator, can improve hospital readmission rates and decrease overall utilization of medical services by stressing patient education, providing patient support and immediate feedback [17].

A Change in Practice

The proposed change in practice would be to employ a nurse dedicated to and knowledgeable about PH empowered to coordinate the complexities of PH therapy in order to prevent hospital readmissions, enhance health-related quality of life [13] and improve patient satisfaction with their health center interactions [1].

In addition, the PH nurse could assist with enrolling PH patients into the PHA Registry and prepare the practice for its application for national level accreditation by the PHA as a designated PH care center [12,13].

Pulmonary Hypertension Care Coordination

The PH nurse coordinator is responsible for the daily management of patients with PH and the coordination of their care dealing with specialty pharmacies, drug manufacturers, outpatient medical and support staff, hospital staff and social services to organize and optimize patient care delivery [13,15]. A qualitative study performed by Yorke, *et al.* describes physical stressors experienced by PH patients, often undetected healthcare professionals, insurance claim benefit officials, friends and family, the effects of these stressors have been referred to as the “hidden disease” [18]. Pulmonary hypertension patients may suffer with a great deal of emotional stressors also, something not always appreciated by a fifteen minute office visit with a physician, highlighting the importance of exceptional healthcare coordination a non-physician caretaker [19].

Strengths and Barriers to a Change in Practice

Prior to implementing a successful change in practice, one must establish overall group conformity and conduct an organizational analysis in order to identify existing practice barriers and strategies for removal of those barriers to change [20,21]. Whether dealing with PH or other disease states, potential barriers may occur during the translation of new clinical knowledge into improved health outcomes. Some examples include excessive volume of data, difficulty accessing the data or inadequate time and skills of the healthcare workers who manage the new clinical information [17,20].

Structural barriers (e.g. financial disincentives to individuals or institutions), peer group barriers (e.g. local standards of care not consistent with evidence-based practice), and professional barriers (e.g. knowledge, attitudes and skills of current employees) exist [20,21] which may limit the growth of a medical practice. Further financial barriers exist as the practice seeks accreditation. As an example, a medical practice may incur additional costs involved in the preparation and application process for designation by the National Committee for Quality Assurance (NCQA) as a Patient-Centered Specialty Practice [19,22]. For this, financial incentives in the form of grants are available and the financial return to meeting health care metrics may help offset the cost concern [17]. The application process for the PHA designation as a PH care center also brings considerable financial and cost-requiring labor considerations. However, presently there exist no such financial incentives to offset these costs to the applicant PH practice.

The Target Group

In order to generate interest in creating the job description of a PH nurse coordinator, one must “engage” a target group referred to as the “stakeholders” by demonstrating to them the potential patient and institutional benefits of such a hire [21]. Engagement and dissemination strategy should be based on a sound understanding of the medical stakeholders to be targeted and the coordination mechanisms most appropriate to optimally reach the particular stakeholder audiences, in this case, patients and the medical practice [21]. For example, the medical and nursing staff, including Department Chair and health care administrators represent one target group - health care institution stakeholders. Patients may be considered an additional target group - the community stakeholders. After engagement of the institution target group, one must gain their acceptance of the importance of creating this new job description through evidenced-based medicine [9,12,15,21,23,24]. The author (M.L.S.) has found presentation to the medical staff at the medical Grand Rounds forum to be a useful way to impart the importance of a PH care center.

The Change Theory in Nursing

Phases leading to a dissemination of change begins with a nursing model or theoretical framework [21]. The Change Theory in Nursing developed by renowned social psychologist Kurt Lewin, theorizes a three-stage model of change known as an “unfreezing-change-refreeze” model requiring a prior routine be rejected and replaced. The Change Theory of Nursing has three major concepts: driving forces, restraining forces and equilibrium followed by three stages of sub-theory: unfreezing, change, and refreezing [25].

Driving forces motivate change if the current process is not working. An example of a driving force - increased patient dissatisfaction resulting in patients choosing to leave a medical practice. As a result, driving forces may facilitate a practice to change - attempts to increase patient volume and satisfaction exemplify a shift in the equilibrium towards change. A state of equilibrium occurs when driving forces equal restraining forces with no change occurring. Restraining forces counter such driving forces as financial barriers to a new departmental position. Driving and restraining forces may hinder change if they push the practice in opposite directions and cause a shift in the equilibrium that opposes change. Equilibrium, however may be shifted by changes occurring between the driving and restraining forces. Unfreezing is the process by which one enables institutions to rid themselves of their old practice habits counterproductive to change and thereby, agrees to necessary change [25].

Three methods may lead to the achievement of unfreezing. The first method - generate momentum or a sense of urgency for the driving forces that direct behavior away from the existing problem. These problems may include poor patient outcomes, dissatisfaction, and costly hospital readmission rates. The second method - lessen restraining forces that negatively affect the movement from the existing equilibrium, e.g. cost consideration for a PH nurse position. The third method: a combination of the first two methods (e.g. patient dissatisfaction and cost consideration) [25].

The change stage is an important stage because it involves a process of change in the stakeholders' thoughts, feelings, behavior, or all three. The refreezing stage establishes the change as the new workflow, so that it now becomes the "standard operating procedure" [25]. Without this final stage, it can be easy for the practice to revert to the prior suboptimal workflow routine.

Implementation

The first essential element for the implementation of change is the creation of a clear vision of the practice's needs and goals and that are "SMART" - Specific, Measurable, Attainable, Relevant, and Time bound [26]. The short-term vision for example, might be to employ a PH nurse coordinator within 6 months of approval to begin to implement the long-term vision. The long-term vision would be the accreditation of the practice as an approved care center within two years of the nurse's employment. Evidence-based clinical practice guidelines may significantly improve practice performance and patient outcomes [21]. In 2011, the PHA (<http://www.phassociation.org>) endorsed the development of a nationwide accreditation program for PH centers [12].

In 2014, the National Clearinghouse Guidelines (NCG) posted a guideline by the American College of Chest Physicians' (ACCP) panel suggesting that whenever possible, PH patients be evaluated promptly at a center with expertise in the diagnosis of PAH, ideally prior to the initiation of therapy [10]. In addition, NCG by ACCP suggests collaborative and closely coordinated care of PAH patients involving the expertise of both local physicians and those with expertise in PAH care [10].

To achieve standard of care through evidence-based practice, research uptake or knowledge translation - having decision-makers assimilate the ideas of experts [21], stakeholders attended a Grand Rounds presentation which was entitled "Pulmonary Hypertension Center Accreditation: For the Sake Our Patients". The clinical problem was presented - the lack of adequate support - a PH nurse coordinator, as was the long-term goal - becoming a nationally PHCC [3,13,23]. Following the Grand Rounds presentation, the feedback from the medical stakeholders was clear. To enact clinically important practice changes, a PH nurse coordinator was necessary to improve collaborative patient decision-making with current knowledge translation activities [20]. Next, the focus was to collect and analyze local data by evaluating cost considerations in researching the role of the nurse coordinator in area PH treatment centers, those located within a 5-mile radius of the greater Philadelphia area. This was achieved by utilizing salary-survey based websites such as www.glassdoor.com. Pay grade was determined based on similar positions within the organization. A job description was created, obtained with the help of an outline proposed by the PHA. A new employee application was completed by the practice managers and a nurse coordinator job description submitted for approval to human resources.

The application process for the nurse coordinator position took 18 months for approval, but with diligence and perseverance, the job description was posted by human resources and filled not long thereafter. According to Lewin's Change Theory, refreezing requires that the stakeholders adapt to the new workflow [25]. Evaluating the practice environment in which refreezing occurred as follows: The PH nurse coordinator was matched with a mentor who provided guidance during a six-month mentorship program by the PHA that helps the nurses adapt to the new role and ensures that standards of practice are upheld [28].

Business cards with the designation "Pulmonary Vascular Disease Coordinator" were printed and handed to each PH patient at their office visit and the RN personally encouraged the patient to contact the PH nurse directly with questions. These actions encourage effective patient communication and confidence that they have some control of their care [21]. Studies show that when patients receive patient coordinator services delivered by a nurse, they are more satisfied with care and more likely to adhere to the treatment plan [15,23]. Although we do not have formal data, verbal feedback has been positive and we believe our efforts may increase patient satisfaction and reduced readmission rates by using a proactive approach to healthcare coordination [27,28]. Under the direction of our PH nurse, three regional PH support group meetings have been successfully initiated and implemented within the first months of the nurse's arrival; high attendance rate and post-meeting attendees' feedback indicate a high level of satisfaction.

The PH physician operates in value-based reimbursement environment and having a dedicated PH nurse to manage existing patients allows the provider to increase new patient visits in the practice, potentially yielding greater financial return [17]. In addition, the PH Program Physician Specialist will be more available to grow and develop the PH team by providing leadership, education and direction [13]. Left in need of study – will the nurse coordinator speed patient visits faster through the office visit, increase the practice revenue in dollars or RVUs.

At the time of this manuscript's submission there were 47 PHA-centers of care for PH in the United States. The care centers will be regularly evaluated with a site visit by the PHA committee ensure the practices continue to uphold the principles of delivering appropriate and effective care to all PH patients [12]. As Sahay et.al, explained, "the mission of the (PHA care committee) committee is to develop exemplary care for all individuals through the promotion of standards of care, accreditation of care centers, education of providers, and the advancement of research in all aspects of PH" [12]. In accordance with the guidelines outlined by the PHA, PH practices not yet including a PH nurse coordinator, exemplify the change state in Lewin's Change Theory of Nursing, wherein opportunity exists to unfreeze the practice from less efficient and patient-centered care [24].

Conclusion

Among the weaknesses of our paper, we have no clinical data to support cost reduction, change in hospitalization readmission rates or long-term patient clinical outcomes following the additional of nursing coordinator in a PH practice. This was not the purpose of our paper, though this certainly should be studied in the future to justify what we believe is a necessary and beneficial health care practitioner for this disease state. As stipulated by the American College of Chest Physicians' NGC, patients should be treated in a PH specialty care center by an expertly-trained PH treatment team [10]. One of the most consistent findings from clinical and health services research is the failure to translate research into practice and policy. A PH nurse coordinator is essential to the success of a PHCC in order to coordinate care, manage medications, monitor response to treatment, improve patient access to the physician, pharmacies and insurance companies and ultimately, act as a patient advocate.

Clinical Pearls

- PH coordination is complex and essential to the success of positive patient outcomes
- Pulmonary Arterial Hypertension is a rare progressive disease that requires careful monitoring by specially trained staff
- Nursing Models can help with facilitating a change in practice (dissemination).

Bibliography

1. Hooper MM and Gibbs SJ. "The changing landscape of pulmonary arterial hypertension and implications for patient care". *European Respiratory Review* 23.134 (2014): 450-457.
2. Rich S., et al. "Primary pulmonary hypertension. A national prospective study". *Annals of Internal Medicine* 107.2 (1987): 216-223.
3. Wapner J and Matura A. "An update on Pulmonary Arterial Hypertension". *The Journal for Nurse Practitioners* 11.5 (2015): 551-559.
4. Galie N., et al. "2015 ESC/ERS Guidelines for the diagnosis and treatment of pulmonary hypertension". *European Heart Journal* 37.1 (2016): 67-119.
5. Chakinala MM., et al. "Managing the patient with pulmonary hypertension: specialty care centers, coordinated care, and patient support". *Cardiology Clinics* 34.3 (2016): 489-500.
6. Simonneau G., et al. "Updated clinical classification of pulmonary hypertension". *Journal of American College of Cardiology* 62.25 (2013): D34-D41.
7. Armstrong I., et al. "The trajectory to diagnosis with pulmonary arterial hypertension: a qualitative study". *BMJ Open* 2.2 (2012).
8. Farber HW., et al. "Five-Year outcomes of patients enrolled in the REVEAL Registry". *Chest* 148.4 (2015): 1043-1054.
9. Brown L., et al. "Delay in recognition of pulmonary arterial hypertension: Factors identified from the REVEAL registry". *Chest* 140.1 (2011): 19-26.
10. Taichman D., et al. "Pharmacologic therapy for pulmonary arterial hypertension in adults: CHEST guideline and expert panel report". *Chest* 146.2 (2014): 449-475.
11. McLaughlin V., et al. "Contemporary trends in the diagnosis and management of pulmonary arterial hypertension: an initiative to close the care gap". *Chest* 143.2 (2013): 324-332.
12. Sahay S., et al. "Pulmonary Hypertension Care Center Network: Improving care and outcomes in pulmonary hypertension". *Chest* 151.4 (2017): 749-754.
13. Stewart T., et al. "Collaborative Care: A defining characteristic for a pulmonary hypertension center". *Pulmonary Therapy* 3.1 (2017): 93-111.
14. Kroening HL., et al. "Patient complaints as predictors of patient safety incidents". *Patient Experience Journal* 2.1 (2015): 1-9.
15. Jones S. "Pulmonary Hypertension Professional Network: Pulmonary Hypertension Patient Navigation: Avoiding the Perfect Storm Advances in Pulmonary Hypertension". *Advances in Pulmonary Hypertension Journal* 15.1 (2016): 32-35.
16. Rich MW., et al. "A multidisciplinary intervention to prevent the readmission of elderly patients with congestive heart failure". *New England Journal of Medicine* 333.18 (1995): 1190-1195.
17. Anderson C., et al. "Benefits of Comprehensive Inpatient Education and Discharge Planning Combined With Outpatient Support in Elderly Patients With Congestive Heart Failure". *Congestive Heart Failure* 11.6 (2005): 315-321.
18. Yorke J., et al. "Impact of living with pulmonary hypertension: A qualitative exploration". *Nurse Health Sciences* 16.4 (2014): 454-460.
19. Ward L., et al. "Patient-centered specialty practice: Defining the role of specialists in value-based health care". *Chest* 151.4 (2017): 930-935.

20. Grimshaw J, *et al.* "Knowledge translation of research findings". *Implementation Science* 7 (2012): 50.
21. Melnyk B and Fineout-Overholt E. "Evidence-based practice in nursing and healthcare: A guide to best practice". Second edition. Philadelphia, Pa: Wolters Kluwer (2011).
22. NCQA. National Committee of Quality Assurance PCSP Recognition Standards (2016).
23. Kingman M, *et al.* "Management of prostacyclin side effects in adult patients with pulmonary arterial hypertension". *Pulmonary Circulation* 7.3 (2017): 598-608.
24. Hoepfer M and Gibbs S. "The changing landscape of pulmonary arterial hypertension and implications for patient care". *European Respiratory Review* 134.23 (2014): 450-457.
25. Mitchell G. "Selecting the best theory to implement planned change". *Nursing Management* 20.1 (2013): 32-37.
26. Melnyk BM. "Strategies for overcoming barriers in implementing evidence-based practice". *Pediatric Nursing* 28.2 (2002): 159-161.
27. Ouwens M, *et al.* "Integrated care programmes for chronically ill patients: a review of systematic reviews". *International Journal for Quality in Health Care* 17.2 (2005): 141-146.
28. Pulmonary Hypertension Association. Recommendations for Improving Patient Outcomes (2013).

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