Real-World Implementation: Nursing Role in Balancing the Art and Science of PAH Risk Assessment

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Comprehensive serial risk assessment in pulmonary arterial hypertension has shown to determine prognosis, monitor disease progression, and guide treatment decisions. The treatment goal is to achieve a low-risk status, which is associated with lower mortality rate. However, use of formal risk assessment in clinical practice has been inconsistent due to numerous barriers related to the multivariable nature of the scores. This publication reviews strategies to increase risk evaluation in daily clinical practice, while emphasizing the role of the RN and APRN in implementing risk assessment calculation and skillful communication to the patient-family dyad to promote open dialogue with shared decision making and improved patient outcomes.

INTRODUCTION

Pulmonary arterial hypertension (PAH), World Health Organization Group 1, is a rare, progressive disease of the pulmonary vasculature leading to right ventricular failure. While no curative therapy is available for PAH, options for medical therapy are increasing. Despite advances in treatment options, morbidity and mortality remain high, reaching median survival for idiopathic PAH of merely 7 years.[1]

Persistent suboptimal outcomes have led to novel care approaches.[2-4] Specifically, comprehensive PAH risk assessment has been developed to determine prognosis, monitor disease progression, and guide treatment decisions based on therapeutic response.[2] Numerous risk stratification tools have been validated to stratify patients into low, intermediate, and high risk categories,[4] including REVEAL 1.0, REVEAL 2.0, REVEAL Lite 2, COMPERA method, SPAHR method, FPHR method, the Bologna strategy, and the Four Strata methodology.[4,5] The overall treatment goal is to achieve a low-risk stratification by escalating medical therapy, which is associated with a lower mortality rate.[6] Routine, comprehensive evaluation of risk status is included in the most recent clinical care guidelines for PAH and is considered current evidence-based practice.[6,7] Early and serial risk assessment is recommended, with escalation of medical treatment until a low-risk status is achieved.[6] Low-risk status is associated with a mortality risk of <5% at year 1 in comparison to >20% for a high-risk patient.[2,7] Regular, multifactorial risk assessment may lead to favorable outcomes for each patient.[8]

Even with this state-of-the-art approach, formal risk assessment in pulmonary hypertension (PH) clinical practice is inconsistent or absent.[3,4] Per recent survey data, merely 59% of clinicians in the United States use risk assessment tools in PAH management.[4] Researchers have identified numerous barriers to risk assessment, including complexity of the tool, number of diagnostic parameters required, need for invasive testing, time constraints, lack of integration into the electronic medical record, inadequate administrative support, and lack of education, training, and awareness.[4,9] While validated risk assessment tools may improve patient outcomes, novel strategies are warranted to increase feasibility of incorporating risk assessment tools into routine practice.[2,3,10]

Current tools use 3 to 13 variables to stratify patient risk, employing modifiable and nonmodifiable parameters, as well as invasive and noninvasive measures.[3,11] However, the literature fails to indicate the most appropriate risk tool for clinical practice nor frequency of use. Given this limitation, the clinician is left to choose the most feasible tool for individual clinical practice, usual diagnostic testing and treatment practices, and overall knowledge of this construct. While clinical testing practices may vary among PH centers, specific parameters may not be readily available for complete risk assessment scoring.

Though several modalities exist to evaluate a patient's risk stratification, it was noted that most patients did not meet the low-risk criteria even after being medically treated for PAH.[5] The majority of patients were deemed to remain in the intermediate-risk category, and that a more granular risk evaluation is required to differentiate the large cohort of *intermediate* patients.[12] This recent refined risk methodology stratifies into 4 strata including low, intermediate-low, intermediate-high, and high risk.[5,11] Boucly and colleagues noted the 4-strata method was more sensitive in measuring changes in risk after treatment and demonstrated better discrimination of short-term and long-term mortality.[11] The hope is that patients and PAH clinicians may make better informed treatment decisions based on this more refined approach. Future studies with the newer 4 strata methodology are needed to determine if a greater number of PAH patients will achieve low risk status.

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Furthermore, previous data have shown that clinician subjective gestalt is inferior to formal, objective risk stratification.[13] Clinical judgment, which can underestimate or overestimate risk, may include subjective interpretation of patient history, exercise tests, hemodynamics, and imaging. Inaccurate risk stratification is suboptimal, as intermediate-risk and high-risk patients face worse outcomes. Sahay and colleagues found that patients with moderate or high activity levels were more likely to have discrepant subjective and objective risk stratification.[13]

The evidence suggests inconsistent use and multiple barriers to risk assessment.[1,4,9] Wilson and colleagues cited the most frequent rationale for inconsistent use as lack of time and lack of technology or electronic health record integration.[1,4,9] Undoubtedly, the evidence supports developing a simple method to calculate a risk score during routine medical visits. A more streamlined tool such as REVEAL Lite 2 or Four Strata methodology may increase the use and sustainability of risk assessment in PAH. The aim of this publication is to share expert PAH allied health clinician experience to mitigate barriers to incorporating risk assessment and effective communication regarding risk into clinical practice, to fully inform patients, enhance shared decision making, and improve outcomes.

RISK ASSESSMENT IMPLEMENTATION

Numerous strategies to ensure timely, accurate, and evidence-based risk assessment may be employed by the PH Care Team and specifically PH nurse clinicians. Due to the growing number of risk assessment tools available, the PH center should build consensus on which tools to use and at which time intervals in a patient's disease trajectory. In our experience, we recommend use of a comprehensive risk tool such as REVEAL 2.0 at index diagnosis and then more streamlined tools at each follow up visit such as REVEAL Lite 2 and Four Strata methodology. Consistent tools allow for longitudinal tracking for individual patients. With certainty, each PH care team member who is responsible for assessing or discussing risk with a patient should be fully educated on routine risk tools and methods for scoring. Nursing PH care team members should have autonomy to complete risk assessment, similar to other PH colleagues such as physicians and advanced practice providers.

Risk score implementation may be completed in multiple formats by the PH clinician. In our experience with formal quality improvement projects, automation of risk scoring tools into the electronic health record (EHR) has the greatest effect on consistent use and tracking of patient risk status.[14,15] In PH centers with access to Epic or Cerner, EHR technical support teams can assist with how to create and implement automated risk scoring. We recommend use of *flowsheets* and *smartphrases* to adeptly include a point of care risk score into medical documentation. This allows longitudinal tracking of scores over time in a streamlined format. Alternatives to use of automated EHR methods include use of web-based calculators such as the PH Outcomes Risk Assessment website,[16] use of risk assessment tear pads, and calculation sheets. PH programs may use support staff to assist with gathering risk assessment parameter results prior to or at the time of clinic visits, as a mechanism to improve documentation.[17]

With the increase in telemedicine in recent years, formal risk assessment may present more challenges. Personal health devices such as smartphones, smartwatches/bands, and various health-monitoring apps provide an increasing amount of information that allow for remote PAH risk assessment in some situations. However, the digital divide and lack of technological access remains a tremendous limitation for a large percentage of patients and areas in the United States. In our experience, the greatest challenge in remote risk assessment is obtaining an accurate 6-minute hallwalk distance from a home setting. Mobile-based 6-minute walk testing is an area of recent study.[18]

NURSES' ROLE IN RISK ASSESSMENT PATIENT ENGAGEMENT

PH nurse clinicians, because of their frequency of contact and close nature of therapeutic relationship, are well poised to assist PH patients and their families throughout the disease trajectory. PAH risk assessment should be included in patient and family education in addition to disease state, medications, self-care management, and goals of treatment. Just as all of nursing care is based, communication regarding risk status should be grounded in principles of ethics, individual care, and shared decision making.[19] In our experience, using compassionate and patient-centered communication techniques, an individual's risk status can be used as a tool to fully inform a patient regarding disease severity, treatment recommendations, and mutual hopes for their future therapeutic response. Patients and their families coping with a serious illness such as PAH require adequate information to make informed decisions about treatment options.[19]

Nurses are positioned to effectively balance the art and the science of discussing a PH patient's individual risk profile. While PH patients are afforded the benefits of a multidisciplinary team from initial diagnosis to treatment, nurses play a vital role in communication, and communication is a powerful therapeutic tool in PH care. At the time of diagnosis or during turning points in the PH journey, communication has the potential to empower a patient with a sense of control while reducing uncertainty, stress, and anxiety.[19] Similar to cancer or other life-threatening illnesses, PH nurses are able to provide information across the illness trajectory related to prognosis and quality of life issues. PH nurses provide a safe place for patients to disclose complex feelings about their diagnosis, receive information to help them maintain a sense of control, and continue to have a sense of hope. Thoughtful discussions regarding PH risk status can improve conversation of values, goals, and preferences and facilitate collaboration with the PH team. Nurses offer emotional support in coping, illness information, and understanding of risk stratification. Similar to oncology nursing, by the nature of the PH illness trajectory, PH nursing demands more attention to palliative care communication as it involves both

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patient and family.[20] Wittenberg and colleagues offer communication strategies based on the COMFORT Communication curriculum, created for the field of oncology but with relevance in the PH disease course (Table 1).[20,21] This provides tangible communication techniques that may enhance patient and family trust and lead to meaningful discussions about PH illness status, care, and treatment decisions.

In addition, patients in the current era are provided with their own medical documentation and deserve a thoughtful and skilled explanation of risk evaluation included in their office visit notes. Specifically, we recommend an open discussion at index diagnosis of risk status, informing the patient with verbiage including a risk category is a tool for the clinician to know "how well a patient may do in the next 1 year." Including risk status in the discussion of PH therapy recommendations has been useful to support the need for more aggressive treatment such as triple and parenteral prostacyclin therapy, as well as refer for lung transplant evaluation sooner. Per previous studies, an informed patient may be more likely to take an active part in their care.[17]

Skillful communication to engage patients with serious PAH findings can be a powerful tool in shared decision making, which is a key component of patient-centered health care. Shared decision making makes patients feel they are listened to and their needs are prioritized, which may have a positive effect on outcome.[22] We find patients and families find comfort in hearing that while they may have evidence of an initial high-risk status, the team of expert PH clinicians will strive to improve the risk profile with close and compassionate care and follow up. We share with the patient-family dyad our hopes for their future, including potential benefits derived from escalation of PH therapy. On the other hand, when we are unable to improve a patient's risk status because of end-stage disease trajectory, use of risk status may also be useful to frame delicate discussions about goals of care and end-of-life decisions. The REMAP framework (REframe, Map, Align, Plan) by Ismail and colleagues provides a tool to enhance a shared treatment plan that is based on patient values and goals (Table 2).[23] These conversations help a patient take an active role in their overall disease management. In various PH illness trajectory scenarios, risk status information allows for patients to make fully informed treatment decisions.

Table 1. Overview of the COMFORT Communication Curriculum[21]

Module	Communication processes
Communication	Understanding the patient's story
	Recognizing task and relationship practices
Orientation and options	Gauging health-literacy levels
	Understanding cultural humility
Mindful communication	Engaging in active listening
	Understanding nonverbal communication
	Being aware of self-care needs
Family	Observing family communication patterns
	Recognizing caregiver communication patterns
	Responding to the varying needs of family caregivers
Openings	Identifying pivotal points in patient/family care
	Finding common ground with patients/families
Relating	Realizing the multiple goals of patients/families
	Linking care to quality-of-life domains
Team	Developing team processes
	Cultivating team structures
	Distinguishing successful collaboration from group cohesion

Table 2. REMAP Model of Communication[23]

Step	Action
REframe	Assess patient's understanding of illness trajectory
Map	Map patient values
Align	Align with patient stated values
Plan	Propose a plan

DISCUSSION

In our experience, building PH clinical team consensus on risk assessment tool timing and use in addition to EHR risk score integration are feasible and effective methods of increasing risk status documentation. Provider barriers may be greatly reduced, and evidence-based clinical care is enhanced. Formal risk stratification is superior to clinician gestalt and should be employed for all Group 1 PAH patients at every visit. Risk stratification is an integral step in the management of PAH patients, and achieving and maintaining a low-risk profile is the goal of treatment.[6]

PH nurse clinicians including RNs and APRNs play a crucial role in balancing the art and science of understanding and communicating risk assessment. Use of formal communication tools and strategies such as the COMFORT Communication curriculum and REMAP model may provide a strong foundation for nurse-patient discussion of risk status. Further evaluation of the effect of patient risk status education on patient treatment decisions and outcomes is warranted.

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