Facilitating and Improving Adherence: The Development of a Pulmonary Arterial Hypertension Self-Care Management Agreement

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Successful disease management includes improvement in a patient's quality of life, particularly when working with patients suffering from pulmonary arterial hypertension (PAH). This success is achieved through a team approach between patients, families, and their health care providers. Providers often prescribe treatment regimens and offer recommendations to slow disease progression and allow patients to become more functional. Adherence to these regimens is critical to the patients' overall morbidity and mortality. Failure to adhere to the recommendations set forth by health care providers often leads to clinical worsening and increased health care costs.[1] We will briefly examine the issue of medication nonadherence and how the development of a self-care responsibilities agreement changed the practice of one pulmonary hypertension (PH) center for the better.

The World Health Organization (WHO) defines medication adherence as "the degree to which the person's behavior corresponds with the agreed recommendations from a health care provider."[1] Perhaps one of the greatest challenges health care providers face is the matter of patient nonadherence. The prevalence of medication nonadherence is astonishing: "In some disease conditions, more than 40% of patients sustain significant risks by misunderstanding, forgetting, or ignoring health care advice."[2] Medication nonadherence can range from never filling a prescription, to stopping medication without notifying the prescriber, to not taking a medication as prescribed, or by not following the recommendations associated with a prescribed medication.[1] The overall outcome of such behavior has adverse consequences. These consequences include "waste of medication, disease progression, reduced functional abilities, a lower quality of life, and increased use of medical resources such as nursing homes, hospital visits, and hospital admissions."[2]

In the field of PAH, the consequences of medication nonadherence can be dangerous and often life threatening, particularly when working with parenteral prostacyclins. PAH medications are unique and complex and warrant a level of respect regarding their safety profiles. In our PH practice, various methods were employed in an effort to prevent nonadherence and improve patient outcomes. These methods included forming a personal connection and level of trust between patient and provider. Additionally, a substantial amount of time was spent educating on disease management and medication nuances. Despite these methods, nonadherence was present in our practice.

In an effort to address the issue of nonadherence, parenteral prostacyclin patients in our practice were observed over a 6-month period. These patients in particular were chosen because of the risks associated with nonadherence in this specific medication category. Patient interactions occurred during inpatient and outpatient encounters to substantiate evidence of adherence with particular safety measures discussed at length with patients during various training/education sessions. The results of this survey demonstrated gaps in what parenteral prostacyclin patients were taught, comprehended, and what was actually being practiced concerning medication safety. These results indicated that further measures were required to ensure medication adherence, safety, and overall patient wellness.

Our program initiated a thoughtful review of the literature to deepen our understanding of patient adherence and strategies that had the potential to change baseline behavior. Medical entities incorporating the use of contracts or agreements to increase medication adherence were investigated, particularly in the field of pain management. The research showed that the effectiveness of such documents regarding opioid use remained unclear. However, there is absolutely *no* research involving the use of such a document in the realm of medication adherence and PAH. Moreover, based on research involving opioid therapy, the use of the term "contract" was highly detested, as it "can be perceived as coercive, can erode physician–patient trust, and implies that failure to agree will result in loss of access."[3] It became clear that verbiage used in these kinds of documents could stigmatize patients. The language chosen could be implied as "mistrustful, accusatory, and even

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confrontational."[3] Therefore, special care needed to be taken when writing such a document. The term "contract" would not be used for the development of an agreement for our PAH purposes.

Based on these research efforts, a PAH self-care responsibilities agreement was developed in order to increase adherence and hold patients and PH team members accountable for discussing and agreeing upon various measures to increase safety and overall health. It was decided among all members of the PH team that this self-care responsibilities agreement would be extended to include all PAH patients on drug therapy, not just parenteral prostacyclin patients as initially planned. It should be noted that a discussion occurred with the hospital legal department, who indicated this would not be a legally binding document.

Over the next 4 weeks, a self-care responsibilities agreement was drafted in collaboration with the PH team including physicians, nurses, and nurse practitioners. This agreement was narrowed to 14 key points deemed necessary for discussion once starting the treatment for PAH. These points ranged from understanding the diagnosis of PAH and the medications prescribed, to the risks of pregnancy and the use of contraception, to not stopping PAH therapies for any reason without discussing with the PH team. A sample of the agreement is included in the Appendix. Each patient was provided a copy of the agreement to read privately. Subsequently, time was allotted to provide further education, discuss benefits, and engage each patient in discussion regarding the points within the agreement. The patient was made aware that the agreement was not a legally binding document. They were then asked to sign the agreement along with a PH team member. This agreement was then scanned into the patient's electronic medical record. By placing this agreement into the patient's chart, it allowed the PH team access to the signed agreement in order to reexamine when necessary if the plan was not being followed or as a refresher for both the PH team and patient in the future.

Patients on all forms of medication therapy for the treatment of PAH were reassessed during inpatient visits and follow-up outpatient appointments for adherence, understanding, and recollection of the key points within the self-care responsibilities agreement. We did not formally score or track adherence issues before and after implementation of the self-care agreement. However, we believe that over the course of 1 year, the gap that had previously existed involving adherence with PAH medications and safety measures prior to the self-care responsibilities agreement had narrowed. Patients appeared more adherent to the safety measures and treatment plan set in place, especially those on parenteral prostacyclins. The level of education, discussion, and shared decision making between the patient and PH team, based on the self-care responsibilities agreement, generated an environment of respect that could ultimately lead to better patient outcomes.

Nonadherence to medication regimens and recommended treatment best practices is a serious challenge that patients and providers struggle with daily. Nonadherence leads to increased health care costs and an overall risk to a patient's health and wellness. Patients with PAH are often prescribed medications and plans of care that, if not followed or administered properly, can have life-threatening consequences. In order to combat our issues with nonadherence, a PAH self-care responsibilities contract was developed and used with all patients on therapy for PAH. The overall outcome of developing and implementing the self-care agreement was positive for our program, which subsequently narrowed the knowledge gap that existed regarding the PAH plan of care. By narrowing the gap, we were able to combat our challenges with nonadherence and ultimately improve the success of our patients' PAH treatment regimens.

References

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SAMPLE COPY

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Pulmonary Arterial Hypertension (PAH) Self Care Management Responsibilities and Plan

The effectiveness and safety of pulmonary arterial hypertension (PAH) management depends on a collaborative approach between the patient and the multidisciplinary team. My PAH management team has educated me in regards to the PAH disease process, classification, testing, and treatment in order for me to manage PAH daily.

I, _____, understand and agree that the following are my self care responsibilities as a patient of the Beaumont Pulmonary Hypertension Center:

1. I will notify the Pulmonary Hypertension Center in advance of any planned tests, procedures, or surgeries in order to receive instructions for care.
2. If I am on intravenous or subcutaneous drug therapy for pulmonary arterial hypertension, I agree to carry my back up medication, back up pump, and supplies with me at all times.
3. I agree to carry the emergency card provided by the Pulmonary Hypertension Center.
4. I agree to notify all other healthcare providers of my diagnosis of pulmonary arterial hypertension and any pulmonary arterial hypertension medications I am taking.
5. I agree to notify the Pulmonary Hypertension Center of any and all medications I take, including prescription medications, over the counter medications, vitamins, and herbal supplements.
6. If I am female, I understand the increased risk pregnancy places on myself and the unborn child. I understand that I must not become pregnant. I agree to utilize 2 forms of contraception or have an intrauterine device placed.
7. I agree to have laboratory testing completed as ordered by the PAH management team.
8. The risks of smoking have been explained to me. I agree to abstain from smoking cigarettes, pipes, cigars, or inhaling any substance into my lungs.
9. I agree to abstain from illicit drug use such as cocaine and methamphetamines.
10. I agree to follow a 2 gram sodium diet.
11. I have been instructed on the importance of using oxygen and agree to follow my written plan.
12. I agree to avoid NSAIDS (non-steroidal anti-inflammatory drugs like Motrin, Aleve, etc.) and nasal/oral decongestants containing pseudoephedrine.
13. I agree to take my PAH medications daily and will not stop taking the medications for any reason unless directly instructed to do so by my pulmonary hypertension physician.
14. I have been instructed on the risks and potential side effects of the pulmonary arterial hypertension medications.

I understand the above and agree to follow this plan

Signature _____ Printed Name _____

Witness _____ _____ Date _____

Appendix: Sample Pulmonary Arterial Hypertension Self-Care Management Agreement.