

# Should Providers Routinely “Prescribe” Support Group Participation for Their Patients with PAH?

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The use of the medical prescription demonstrates a significant evolution from the first uses of the symbol  $\mathcal{R}$ , an abbreviation for the Latin word *recipe* meaning “to take,”<sup>1</sup> until the present time. Early historical treatments that physicians prescribed were typically medical remedies compounded by the pharmacist. This was followed by orders for dispensing pre-packaged, manufactured medications in the post-compounding era. The current intention of a medical prescription has broadened further to now be considered, “. . . a health-care program implemented by a physician or other qualified practitioner in the form of instructions that govern the plan of care for an individual patient.”<sup>2</sup> In the spirit of this definition, non-medication prescriptions, including those for specific levels of exercise, dietary guidelines, and treatment modalities such as massage therapy, are specifically prescribed by medical practitioners to emphasize their belief in its value for treating a medical condition. This concept of formalizing recommendations regarding non-medication treatments as a prescription to patients has been previously studied. In New Zealand the so-called “Green Prescription” utilized by general practitioners who wrote an exercise prescription to improve the level of physical activity of their patients showed a significant impact over verbal counseling alone.<sup>3</sup> Similarly, an investigation employing a “bibliotherapy prescription,” which instructed patients suffering from

depression to read a self-help book entitled *Feeling Good*, demonstrated that a behavioral prescription was as effective as standard therapy, which often included medications.<sup>4</sup> So, in the setting of treatment of patients with pulmonary arterial hypertension (PAH) and an *Advances* issue devoted to the Pulmonary Hypertension (PHA) Association’s International PH Conference of 2014, we might consider the following question: Should providers routinely “prescribe” support group participation for their patients with PAH?

Limited data suggest that recommending support group participation to their patients is not currently a majority practice among health care providers treating PAH. Of all patients who made initial contact with PHA through the peer support program since February 2013, 48% specified how they learned of PHA. Of those patients, 17% indicated that they learned about PHA from their healthcare provider compared to 42% of participants who indicated that they learned of PHA through an internet search.<sup>5</sup> While other support groups (ie, non-PHA support groups) may be recommended by practitioners to their patients, recommending or prescribing a support group is not typical following a PAH diagnosis. For support group prescribing to become routine practice, practitioners would likely seek information similar to other treatments they now prescribe: data supporting safety, and effectiveness, which is subsequently

affirmed by positive experiences from their patients.

Without high quality studies describing the safety or risk of support group participation for patients with PAH, practitioners are free to hypothesize regarding the possible downsides of support group participation, which seem likely to be minimal. Patients may read or hear misinformation, misinterpret well-meaning information, and become acquainted with patients whose PAH worsens over time. These and other possibilities should be considered; they argue for recommending participation in a support group with a good medical foundation as well as one that recommends that those who may become distressed after participation address all concerns with their PAH team and other medical providers. Proceeding with the premise that support groups with these good foundations are available to patients, might we expect that participation is likely to be effective in improving their disease outcomes? As with the question of safety, studies specifically addressing disease outcome measures in PAH are lacking, requiring that one consider data regarding support group effects on other chronic, life-threatening diseases.

Breast cancer, like PAH, is a life-threatening disease predominantly affecting women that has some research data regarding the effects of support groups on illness outcome. The data have been somewhat inconsistent in terms of specific benefits observed; however, in one large prospective study supportive-expressive group therapy improved mood and the perception of

pain, particularly in women who were initially more distressed. This same trial did not evidence prolonged survival in women with metastatic breast cancer in the support group arm, however, as was seen in prior other smaller trials.<sup>6</sup> In contrast, a large meta-analysis of cardiovascular disease patients that included 23 trials (2024 patients versus 1156 controls) observed that group psychosocial support improved anxiety and depression, biomarkers such as systolic blood pressure, heart rate, and cholesterol level, decreased event recurrence rate, and also reduced mortality. The authors recommended that psychosocial support components be included in cardiac rehabilitation programs.<sup>7</sup> Obviously, this is just a small sampling of the data regarding support interventions, however, it suggests that measurable benefits regarding illness trajectory may be attained from support group participation.

While medical practitioners rely on quantifiable data, such as shown in these studies related to breast cancer and coronary artery disease, in deciding to prescribe specific treatments, the patient response to these treatments may reinforce or discourage continued prescribing. Extensive positive data are available in this area of the patient-reported outcomes for support group experiences, although generally not in a scientifically/statistically analyzed format.<sup>5</sup> The individual data points, which in this case are the patient testimonials, may be the most influential. Many practitioners who have cared for patients with PAH have listened to descriptions of the peer-to-peer sharing that has provided irreplaceable affirmation, information, and inspiration

from fellow support group participants. The experience of support group may be so transformative that some patients have been moved to write and publish their experiences. One such account of an individual diagnosed with PAH who attended her first PHA International Conference in 2004—which was a patient support group on a grand scale—wrote regarding the experience of meeting others with this rare disease, “I am one of the few but I am not alone anymore . . . I don’t have to hold onto this disease and feel it is only me. I can loosen the grip and share the load with others.” Although routine support group attendance may not be well-suited for everyone (and some may attend once or only sporadically), for many the benefits are immeasurable and probably worthy of prescribing for most patients with PAH.

In summary, the medical prescription has evolved from its original intent as a recipe for compounding medicinal agents to its present form, which may include behavioral recommendations for disease management. Data suggest that prescriptions from medical practitioners to increase physical activity are effective in promoting exercise compared to verbal recommendations alone. Investigations of prescribing self-help reading for patients with depression showed benefits that approached those achieved with standard care. The absence of studies of psychosocial support group effects in PAH leads us to look at support group effects in the setting of other serious, chronic illnesses such as breast cancer and coronary disease. Support group participation in these areas may have a range of significant patient benefits including the potential to improve sur-

vival. These measurable benefits on patient’s disease course are welcome findings for chronic illnesses that may accompany the patient-reported salutary effects on mood, anxiety, and decreased feelings of isolation reported for patients with PAH. So, while many patients may still identify support resources via the internet, a written recommendation to participate in a support group may increasingly be considered (to use an old saying) “just what the doctor ordered.”

## References

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