

Why should PH clinicians care about patient quality of life?



Dr. Jason Weatherald

On the last day of the PH conference, Dr. Jason Weatherald spoke about the importance of patient-centered care and quality of life (QoL) in the PH community. According to Dr. Weatherald, PH is a complex disease that significantly impacts QoL, more so than other diseases. But why should clinicians care about it? Dr. Weatherald set out to answer this question. Clinicians should care about QoL because it is the most important expectation from treatment and is directly related to survival—people with better QoL tend to live longer and do better.

However, disease management strategies for PH often do not take patient experiences and quality of life into account, explains Dr. Weatherald. Current treatments largely only treat the underlying disease and fall short of addressing things that improve QoL, such as mental wellbeing and relationships with friends and family.

Incorporating QoL measurements in future PH research can ensure that in addition to treating the underlying disease, new interventions and therapies also have a positive effect on patients' daily lives, says Dr. Weatherald. A shift to a patient-centered care model where patients are engaged in the decision-making process around their own care can empower patients and could lead to better overall care and patient outcomes. "In a practical sense, patients should be able to discuss their symptoms and experience of their illness, including the psychosocial impact of PH," says Dr. Weatherald, "and clinicians should be receptive to this input and be able to apply it to the patient treatment models."

Contributed by: Miriam Bergeret, living with PAH since 2016, PHA Canada Knowledge Translator

—

In a practical sense, patients should be able to discuss their symptoms and experience of their illness, including the psychosocial impact of PH...

—