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Vol 9, No 1 (Spring 2010)

I have read the Winter 2010 issue of *Advances in Pulmonary Hypertension* with great interest. The theme of this volume was quality of life with emphasis on the role of the multidisciplinary team in supporting pulmonary hypertension (PH) patients.

I've been fortunate to work with PH sufferers and their families within the context of a multidisciplinary team of health providers for more than a decade. During that time the numbers of highly qualified, dedicated multidisciplinary professionals that I have met in Europe and the US who have dedicated their careers to this group of patients stand out clearly for me. The depth and breadth of knowledge and experience represented by this group strikes me as an underused resource when investigating and studying this patient group.

Here at Cambridge in the UK we have formally studied quality of life (QoL) when we developed the Cambridge Pulmonary Hypertension Outcome Review (CAMPHOR). From the many proposed theoretical models as to what constitutes quality of life, we used the needs-

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based model proposed by Hunt and McKenna, which draws on the work of theorists in the field of human motivation who argue that human needs are the foundations of quality of life, and that individuals are motivated or driven to satisfy their needs.<sup>1</sup> As a model on which to hang an outcome measure, this has great merit. But most specialist nurses are aware that quality of life is basically determined by how we *feel*. No veteran nurse will not have had experience of a severely ill patient who somehow transcends his or her illness. Such people bring light and warmth to people around them, and to spend time with them is a cheerful, even uplifting experience. But how do they do it? How do they reach such a place? This should be studied and the results utilized to help our patients.

Physicians, with all the scientific advances at their disposal, fight to reduce or eradicate symptoms. That is their purview and it is of primary importance, but improving a 6 minute walk by 30 meters may not impact how a patient feels on a day-to-day basis, and surely the essence of care is to make people *feel* better. We cannot sidestep the disease. Our patients face great uncertainty, disruption to lifestyle, and, for most, a shortened life. A cure is not yet available. Research by nurses, physiotherapists, and others should focus on how to improve the patients' day-to-day lived experience. Such knowledge will only come if all aspects of living with this disease are studied using known, well-validated research methods. Qualitative research has been undervalued by many scientists, but there is no better way of systematically identifying issues that affect PH patients and successful strategies that may help them and their families. Nursing, with its emphasis on care and communication, lends itself naturally to this research method.

Nearly an infinite scope for nurse-led studies exists to help us learn how to improve patients' adaptation to and appreciation of life on a day-to-day basis. Gihl, in her very interesting and thorough review of the literature on health-related quality of life, notes that improving HRQoL is a dynamic process. Adaptation may occur over a period of years. Those of us that are committed to this specialty have the perspective, and perhaps the responsibility, to actively use our experience and our access to such patients to seek a greater understanding of how patients adapt to and even enjoy life with PH. We should study the examples of very sick people who succeed in living good quality lives by their own perceptions. That is something we should seek to understand and achieve for all our patients.

1. Hunt, SM, McKenna, SP . The QLDS: A scale for the measurement of quality of life in depression. Health Policy 1992;22:307

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