

Ivan Barofsky

On Dec 21, 2025, we lost a treasured colleague and friend, Ivan Barofsky, who died peacefully at home at the age of 90. He was a psychologist, and his mind remained active and engaged through a long and diverse career that began with research in biological psychology, then re-specialization as a clinical psychologist. His change in career direction marked the beginning of a longstanding research interest in health-related quality of life (HRQL) that continued well into his retirement.

Ivan received his BS in Biochemistry from the University of Chicago in 1956, an MA in psychology in 1960 from Florida State and his PhD in 1964 with a dissertation entitled “Sensory Aspects of Thermoregulation.” He then held a number of research positions, including 4 years as a research psychologist with the US Army Research Institute of Environmental Medicine (1964-1968); 2 years at the Worcester Foundation for Experimental Biology (1968-1970); and 6 years on the faculty of the Massachusetts College of Pharmacy (1970-1976). He next relocated to the Washington, DC area where he had multiple research positions including at the National Institutes of Health (NIH), University of Maryland Nursing School, and Johns Hopkins School of Medicine.

In the 1980s, major events in Ivan’s personal life led him from lab-based academic research to clinical practice and trials. His wife of 22 years Anna Lisa Barofsky (nee Kaplan), an endocrinologist by training, had an initial bout with cancer before their son Jeremy was born. Sadly, the cancer returned and she passed away in 1987 when their son was not yet 6. Their years battling cancer together and this loss had a profound impact on Ivan, leading to his retraining as a clinical psychologist and realigning his research interests to cancer and HRQL. As his son said, “His work was bound up in her experience [of medical care and the medical system].” An important example is his involvement in one of the earliest randomized clinical trials in oncology to specify health-related quality of life (HRQL) as the primary endpoint (Sugarbaker et al, 1982). This paper yielded counter-intuitive HRQL results, powerfully demonstrating the importance of giving patients a direct voice in clinical trials. The authors had hypothesized that saving a limb would yield better HRQL outcomes than limb amputation; the patient-reported HRQL data disproved that hypothesis. This study prompted further clinical work to improve limb-sparing surgical techniques in soft-tissue sarcoma. Ivan went on to publish numerous papers, mainly in cancer, but also obesity and weight loss, often with a focus on quality of life.

In 1993, Ivan joined forces with and became partners with Penelope Keyl, a highly respected epidemiologist at Johns Hopkins School of Public Health. The next year, Ivan and his son moved from the suburbs of Washington DC to Wyman Park in Baltimore to live together with Penelope. From that time, Penelope became an important part of his family and a stepmother to his son. Ivan and Penelope remained partners until 2008 and friends to the end.

A few years earlier in 1990, Ivan had begun working at the Bayview Medical Center in the Department of Psychiatry and Behavioral Science (later receiving a joint appointment in the Department of Medicine as well) at Johns Hopkins, with an interest in chronic pain, digestive disorders such as irritable

bowel, and swallowing disorders. His work at the Multidisciplinary Chronic Pain clinic at Bayview meant that he supported patients with challenging chronic pain, dysphagia, and irritable bowel symptoms. He did this work with such hope and optimism that some patients would still send thank you cards years later. During this period, Ivan joined the emerging HRQL research community that coalesced into the International Society for Quality of Life Research (ISOQOL) in 1993, serving as its 5th president in 2000-2001. His training in psychology gave him important knowledge, skills and insights about methods for assessing subjective phenomena, which he applied to HRQL assessment. Importantly, he was a trailblazer in advocating for the use of cognitive sciences to enhance methods for assessing HRQL, which of course apply more broadly to patient-reported outcome measures (Barofsky 2000, Barofsky et al 2003, McColl et al 2003, Barofsky 2003). He was also instrumental in the formation of the “International Study Group on Cognitive Aspects of Quality of Life Research” which met at the annual ISOQOL scientific meetings for some years. In 2021, he was awarded the ISOQOL President’s Award in recognition of his important and varied contributions to the field. As he prepared for his President’s award speech, he realized he was the first President of ISOQOL to issue the award. During his early years with ISOQOL, he had also made an early suggestion to add regional chapters to the Society, a suggestion that is now a reality in the vibrant Regional Interest Groups.

After his retirement, Ivan and Penelope moved to Cape Cod (near Boston, Massachusetts) where he founded the Quality of Life Institute, and published his book, *Quality: Its Definition and Measurement as Applied to the Medically Ill* (2012). This was a weighty tome – both literally and metaphorically – that reveals his intellectual curiosity, acuity, scope and determination. Just shy of 500 pages, it covers a diverse and far-reaching array of topics – too many to list, and is available from Springer here <<https://doi.org/10.1007/978-1-4419-9819-4>>. Over the last few years, Ivan was also working on a book titled *On Values: A Psychological Perspective* (unpublished), and a series of interviews with early contributors to the field (unpublished, recordings now archived with ISOQOL) which he called the ISOQOL Oral History project. In addition to the above projects, he frequently taught classes at the Academy of Lifelong Learning (ALL) on Cape Cod, including a course on human rights related to the right to health care and was working on a paper on the individualization of qualitative assessment given advances in immunotherapy and precision medicine. Ivan’s career spanned 56 years from his first position as a high school science teacher in New York City to the publication of his book in 2012. Over the course of his career, he contributed 35 peer-reviewed publications, 54 journal articles and book chapters, 81 research abstracts, wrote 2 books, and edited 5 others. Even though he retired from Johns Hopkins in 2001, he remained intensely interested and engaged in the fields of psychology and HRQOL and continued to contribute.

Ivan was an accomplished researcher and clinician, a man whose personal experience shaped his work. But his personal qualities are important to remember as well. A conversation with Ivan was always intellectually stimulating. He was warm, creative, fully present, and full of humor and curiosity. A personal visit to his house on the Cape might include a tour of his garden, listening to him read selections of his poems, or watching a game of baseball (his beloved Baltimore Orioles) or a basketball game. During his retirement, he also took poetry classes at ALL and for years shared an annual collection of poems, which he

published as an end-of-year booklet to share with friends and family. In another creative endeavor, inspired by his poetry class and classmates, he wrote a book called “Children’s Poems for Adult Children,” which was illustrated by a friend. He was also an organizer of family reunions, which he joyously named “Camp Bar-of-Sky,” a yearly gathering at his home and then at the homes of other family members, creating an important tradition. He was generous with his advice for living, weighing in on challenges and aspirations alike. One felt that he was genuinely interested in these personal details.

For 30 years or more, until his eyesight limited his ability to travel, Ivan was a regular presence at the ISOQOL annual conference, always offering his perspective, wisdom, and humor. We will miss him.

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