

HONORING the Life of BARBARA GANDEK MS, PhD

Dr. Barbara Gandek, a stalwart ISOQOL member since its inception, passed away March 4, 2020, following a fierce battle with cancer. She was in the early years of her 6th decade of life. In her published obituary, many laudable facts were reported. We honor those here as well as the person. Barbara was a friend, mentor, confidant, counselor, and educator (sometimes multiple roles at the same time) to so many people whose paths she crossed.

(FAMILY) While we, her colleagues, did not know her family well; we knew of her great love for her three nephews. A contributor from her family wrote: 'it was easy to see her great love and joy in being close, trusted and deeply involved in their lives (her nephews); and how kind, smart, warm, supportive and funny (in a good way!) she was in general as an aunt as well as to her extended family". Many of us hope we were considered in the extended family umbrella; we know it felt that way if you knew Barb.

(FRIEND) A newly minted clinician who just completed her clinical doctorate, joining the Health Institute in the summer of 1990 recalls - "the first time I met Barbara I had no idea that a '486' computer even existed; Barb explained how John [Ware] had a vision of how important this equipment, our 'lab equipment' would be in advancing our work. We were using 286 models. Barbara was, almost instantly, a trusted friend; she was a mentor and introduced me to and helped me learn SAS, especially the all-important semicolon needed at the end of a line of code". She was genuinely kind and so generous with her time; I will forever respect her integrity, and generosity and treasure those good 'old times'.

Friends and colleagues were devastated by her passing; we knew this would happen but always thought we had a long time until the future arrived. She was very gracious and always had time for a friend. "I happened to call Barbara the night she came home from rehab--almost the very minute. Surprised that I called just then, she said, 'Call me back, stop by, but I just ordered food and I am starving!' That was Barb, straightarrow honest! I will miss our non-stop flights to and from ISOQOL, where we could finally catch up."

(FRIEND/ PROFESSIONAL) Her absence is a huge loss to the field of patient-reported-outcomes measurement. Barbara was a highly-valued colleague to anyone and everyone with whom she worked; she had the highest standards and was a model of integrity for us. She inspired us just by being herself; she modeled tenacity each day; for Barbara, it was not an option to be anything less. She had the highest standards of excellence for her work as well as that of any collaborators who benefited greatly from her high standards. She was intelligent, resourceful, funny, kind, and persistent. In her lifetime, cut short, she, quietly, contributed so much; more than others do in a longer lifetime. She soldiered on despite her health challenges. Barbara was a treasure for the field and an unsung hero in so many ways.

After earning a BS in Economics from Swarthmore College, she came to Boston to study. Barbara earned a Masters in Health Policy and Management from the Harvard School of Public Health and a Ph.D. in Clinical and Population Research from the University of Massachusetts Medical School.

For Barbara Gandek, her work was an avocation. She started by growing into an innovator in the use of insurance claims data to study health care utilization patterns. Then Barbara joined the Health Institute at Tufts Medical Center starting as a project director and growing in expertise and her command of the evolving field. For more than 25 years, she steadfastly grew while helping countless others, for example, clinicians, and health policy students, all new to the concept of health-status assessment. Barbara was more than the work she so precisely accomplished, she was also dedicated to improving the science by mentoring and educating, and contributing to the knowledge of many who went on to study and apply patient-based assessment nationally and internationally.

Over the next decade Barbara's dedication to the field was accomplished as a Scientist with Health Assessment Lab, and as Senior Scientist and Director of International Research & Development with QualityMetric Incorporated, and finally, as Director of Research for the John Ware Research Group. Dr. Gandek held appointments as Assistant Professor at the University of Massachusetts Medical School, and instructor at Tufts University School of Medicine.

(PROFESSIONAL WORKS) Her work with the SF-36® survey began in 1990 assisting early SF-36 adopters, and she co-authored the first SF-36 manual in 1993 along with six other SF user manuals over the next 15 years.

Barb also worked extensively and directly with researchers around the world who were translating and validating the SF-36 as part of the International Quality of Life Assessment (IQOLA) Project. Barbara was often sought as an expert resource, or the voice of logic to help others navigate their parts. She was involved in the development of more than 300 translations and co-edited the November 1998 issue of the Journal of Clinical Epidemiology which contained 32 peer-reviewed papers from the IQOLA project.

In more recent years Barbara's fidelity grew with and into contributions to item response theory (IRT) and computerized adaptive testing as these became more widely used to measure patient-reported outcomes (PROs). Barbara worked on many IRT projects and was a member of the team that developed and disseminated the PROMIS® physical functioning item bank. Her work was critical in ensuring sound psychometric properties of specific PRO instruments.

Barbara loved learning, a consumer and creator of new knowledge as well as a teacher sharing all that she could to help others. She was co-author of more than 50 peer-reviewed publications and edited for many journals. She is also remembered as an impactful teacher, especially by classes of skeptical young physicians to whom she devoted time helping develop an understanding of, and respect for PROs. A colleague who co-taught with her at Tufts Graduate School of Biomedical Sciences, affiliated with the Tufts CTSI¹ at Tufts Medical Center recalls, Barb, amazingly, and consistently showed up on time, prepared, and ready to work, despite significant health limitations".

¹ Tufts Clinical and Translational Science Institute

Not so widely known, during many of the aforementioned accomplishments, Barbara endured challenges so great that others would have sought to surrender to their limitations; not Barbara. She was not giving up. Barb finished her Ph.D. while successfully battling breast cancer. Afterward, into her last year of functioning, she first-authored four PRO articles before succumbing to brain cancer.

Dr. Barbara Gandek was an acknowledged expert in the field of healthcare outcomes measurement science; a treasure to the field is lost. We mourn that loss and celebrate all of her contributions to our lives, professionally, and personally. There are many variants defining a HERO; a warrior, a person admired for achievements and noble qualities, one who shows great courage. Let us celebrate our hero, friend, and colleague for the person she was and for what she left us to aspire toward.