

Lillie Shockney

Breast Cancer Survivor, Advocate, and Researcher

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Lillie Shockney is the Administrative Director of The Johns Hopkins Avon Foundation Breast Center and an Assistant Professor in the Department of Surgery at The Johns Hopkins University School of Medicine in Baltimore, Maryland, USA. Lillie is a registered nurse, holds a BS degree in Health Care Administration, a Masters in Administrative Science, and has advanced knowledge in healthcare management and administration. Having worked at Johns Hopkins since 1983, Lillie served as the Director of Performance Improvement and Utilization Management from 1987 through 1997. Since then she has served as the Administrative Director of the Avon Foundation Breast Center. She is responsible for quality improvement and patient-education programs, leads a survivor volunteer network, and is responsible for community outreach. She has gained local, regional, and national esteem for her innovative work and dedication to her patients. Lillie is the recipient of copious awards, to name just a few: the *Outstanding Women of America Award*; *National*

Silver Medal Award; *National Circle of Life Award*; the *American Cancer Society's (ACS) Voice of Hope Award*; *ACS Lane Adams Award for Excellence in Caring*; *2002 ACS Faces of Breast Cancer Award*; *2002 Oncology Nursing Society Award for Excellence in Breast Cancer Education*; *Impact Award* from the National Consortium of Breast Centers for lifetime achievement; as well as the *Komen Award* from the Maryland Affiliate in 2003. In 2004, she was a finalist for the *Lance Armstrong Foundation's Spirit of Survivorship Award* and was also selected as one of the *Top 100 Women in Maryland* for her leadership and community service efforts.

While Lillie is primarily known as a breast cancer survivor and patient advocate, she has recently embraced the concept that both breast cancer survivors and patient advocates need to take an active role in breast cancer research. Lillie was diagnosed with breast cancer in 1992 at the age of 38. Her earliest experiences with research focused on writing educational books and breast cancer treatment articles.^[1-5] She published her first book, *Breast cancer survivor's club: a nurse's experience*,^[5] in 1996 and her second, *Journey of hope: couples speak out about breast cancer*,^[2] shortly thereafter in 2001. As a patient advocate, she has also written patient guides^[1] and is a national public speaker on breast cancer.

Lillie has also been very involved in addressing the psychological needs of patients, during and after treatment, through the development and implementation of survivor retreats, focusing on patient education and empowerment in the face of the difficult decisions survivors continue to face across the continuum of care. Recently, I have been fortunate to

have had the chance to get to know and work with Lillie on a collaborative effort to promote the intersection of advocacy and health economics.^[6] From a traditional academic viewpoint, Lillie has taken an unconventional path in her academic work, a trail grounded in her experiences as a patient, and, as such, her story and experiences are of ideal relevance for *The Patient*. Lillie serves as a testament to an important trend for patient advocacy, both in the USA and in geographically and culturally diverse corners of the globe: the movement towards patient-centered outcomes research.

The Path into Patient Advocacy

Lillie has worked for many years as an oncology nurse, yet she firmly believes that it was her experiences as an oncology patient that drew her to patient advocacy. In 1992, Lillie was diagnosed with multicentric invasive ductal and ductal carcinoma *in situ* stage. In the subsequent days, months, and years as a cancer patient and survivor, Lillie came to realize that high-quality care as defined from the clinical viewpoint was not sufficient for patient needs, comfort, and support. She experienced firsthand many concerns and emotions – including fear, anxiety, and psychosomatic symptoms – that, at the time, were not a part of clinician discourse. Patients, she realized, needed someone to talk to about the processes, not just the outcomes, of care.

Upon her return to work, Lillie offered to serve as a volunteer peer mentor to help guide newly diagnosed breast cancer patients through the immediate treatment process, as well as to provide guidance and support regarding long-term lifestyle changes that many survivors would need to make in the wake of recovery. What she initially anticipated as being an advocacy effort of 6 hours per week quickly soared into an additional 24 hours on top of her clinical shifts at the hospital. These early advocacy efforts were focused on palliative care, motivated by her need to ensure that, as death approached, women and their families received the necessary assistance in achieving closure. This focus on end-of-life needs juxtaposed with prevailing efforts in medical oncology that focus on promoting longevity at all cost.

Through her work, Lillie brought comfort, by offering information, a willing ear, and often an empathetic hug, to those, who by traditional outcomes research terms, the healthcare system had nothing more to offer.

A Vision for the Future of Healthcare

Lillie's vision for the future is to strive for a closer relationship between caregivers (particularly the primary care physician) and the patient. To optimally limit patient anxiety, this relationship must engage patients as active decision makers and participants in the healthcare they receive. From an economic point of view, Lillie also believes that fostering this closer working relationship will result in the consumption of far fewer healthcare resources. For instance, many cancer survivors believe that they must engage in perpetual screening in order to detect any reoccurrence of disease. Through a closer working relationship with their physician, many of these women may better understand that this is simply not the best course of action; in fact, perpetual screening more often than not simply results in needless anxiety for the patient and wasted resources for the healthcare system. Instead, by encouraging a greater role of the patient in treatment decision making, patient-physician lines of communication will facilitate not only the exchange of this information to the patient, but also a better understanding of the patient's needs to the caregiver. Such a movement would prevent the waste of important healthcare dollars on unwarranted magnetic resonance imaging, CT, ultrasound, blood work, and other nuclear medicine tests that incur great costs with potentially little yield.^[7,8]

Lillie exemplified her vision for the future of healthcare through a somewhat unorthodox project that she has recently been involved in as a member of the Patient Advocacy Taskforce at The Johns Hopkins Medical Institutions. Her involvement began when a group of clinicians sought her advice about communicating with the family of a deceased breast cancer patient regarding a rapid autopsy research study they hoped to undertake. The project aimed to identify the extent of metastasis in breast

cancer patients in order to evaluate the prognostic factors and biomarkers of metastatic tissue where cancer spreads. The eventual goal of this work is to understand how to prevent cancer from ever leaving breast tissue, a feat which, if accomplished, could eliminate mortality from the disease.

Lillie was insistent that family members were not the right people to talk to, but that the patient, before she died, needed to be involved. This idea went against the traditional notion that upon death, patients lose the right of autonomy. Lillie argued that this loss of right at death was a daunting prospect for someone who is facing death, and that discussing rapid autopsy with the patient could be an empowering endeavor. Furthermore, to evoke the concept of continuity of care, Lillie argued that consent from the patient and her family needed to be obtained by the pathologist who would be performing this final procedure on the patient. Patient communication skills are not on any curriculum for pathologists, frankly because they have not traditionally needed this skill set. Lillie argues that if we are going to move the culture of medicine to treating the patient as a whole human, rather than as a subject or specimen, then even those who have not traditionally worked with patients need to become part of the patient support network. It is certain that having a pathologist talk to patients about autopsy has taken patient advocacy and empowerment to a completely new level. This completes the healthcare team circle, which is now, for the first time, being seen as including all healthcare providers involved in the patient's care including those taking care of her post mortem. The patient, of course, is at the center of this circle.

The Main Challenge

For Lillie, the main challenge in adopting a more patient-centered view of medicine is acknowledging its absence as a problem. Many in medicine, and especially in oncology, remain far too focused on outcome, so that they often forget that the patient has to live through the process, irrespective of those outcomes. Lillie believes that patient-centered care must be focused on involving and empowering the

patient – a position that is at the core of *The Patient*.^[9] As Lillie puts it “The more we empower patients the more they are satisfied, even if they are going to die.” One can see her commitment to palliative patients in the questions she continues to probe, “How can we help women who are living with metastatic cancer? How can we handle issues of regret (why did I not get enough tests)? How do we balance evidence and the risks (but here risks are in human, not economic, terms)?” To advance patient-centered care and outcomes research, Lillie challenges us all to think outside the box and not to remain rigid in our thinking and research practices. This will of course require a paradigm shift.^[6,10]

The Changing Role of the Patient Advocate

Given the many recent advances in breast cancer treatment, Lillie sees the role of patient advocates as becoming more research oriented, recognizing that through research we create innovation and better quality care for breast cancer patients in the future. Currently for Lillie, the movement from patient advocate to patient advocate researcher is a logical transition, but it is not a step that she would have envisioned 15 years ago. Recent trends in breast cancer, such as hormone therapy and genetic testing, have made it necessary to involve patients, and, as such, one needs to not only inform the patient about medicine but also to inform medicine about the patient.^[6] Much of this advocacy work remains a grass roots effort, but there is also a need for patient advocates to work at the macro level – and especially through the research process.

By focusing attention on the patient, the most important stakeholder in medicine, Lillie thinks that *The Patient* will not only publish important research results advancing the voice of the patient in healthcare decision making, but will also play a role in helping to define what is ‘good’ in medicine. The journal, she believes, will play an important and groundbreaking role in identifying, promoting and, most importantly, explaining research methods that can be used to study the patient's perspective in a scientific way. In the clinical arena, breast cancer

research is a potentially important springboard for propelling the idea of patient-centered outcomes research into general discourse, particularly given the remarkable scope and breadth of the activities of patient advocates.^[6] Lillie spoke of Dr Marisa C. Weiss as another pioneer in patient-centered outcomes research. Dr Weiss, a radiation oncologist, is the founder of www.breastcancer.org,^[11] an online resource for medically-reviewed breast health and breast cancer information. Lillie also spoke of the Young Survival Coalition[®],^[12] an organization founded in 1998 by three young (all aged under 35 years) breast cancer survivors, as well as those who support patients directly or by providing financial support to groups such as the Avon Foundation^[13] and Susan G. Komen for the Cure[®],^[14] as key contributors in advancing patient-centered outcomes research.

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