Sidney Katz, MD: A New Paradigm for Chronic Illness and Long-Term Care

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Dr. Sidney Katz's legacy to the field of gerontology is internationally recognized as his success at developing standardized measures and processes, beginning with the activities of daily living index, for the functional assessment of older adults with chronic conditions necessitating long-term services and supports. That work served as the bedrock for his subsequent major accomplishments, which improved rehabilitation services through interdisciplinary team work and attention to the patient-family constellation; reformed the regulation of nursing homes, refocusing it on resident outcomes and quality of life; and promulgated the concept of active life expectancy as a new approach to measuring the quality of later life. Few other scholars and researchers in the history of the field of aging can claim one, much less multiple monumental contributions leading to major advances in the treatment of chronic illness and the quality of long-term care.

Key Words: Activities of daily living, Active life expectancy, Nursing home regulation

Few scholars and researchers in the field of aging have significantly changed our thinking about chronic illness and long-term care as did Dr. Sidney Katz. He was an internationally renowned geriatrician and health services researcher, most widely known for the index of activities of daily living (ADLs) that he and a team of health professionals developed at the Benjamin Rose Hospital in Cleveland, Ohio. They had set out to create a tool to measure gains and losses in physical function and serve as the basis for making prognoses for patients treated at the hospital for strokes, hip fractures, and other disabling conditions. This approach had no precedent when the first article published by the Staff of the Benjamin Rose Hospital (1959) detailed a new classification of functional status in ADLs. A subsequent article (Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963) published in the Journal of the American Medical Association on the index of ADLs as a standardized measure of function in studies of illness and the aged people is one of the most frequently cited publications in the health sciences literature (Gurland & Maurer, 2012).

In response to frequent questions about how he became a geriatrician and developed the ADL index, Dr. Katz explained his entry into the field was somewhat circuitous (Hoban, 2008). During medical school at Western Reserve University, his interest was in pathology, specifically virology, for which he received a fellowship from the American Cancer Society after graduating in 1948. When the Korean War escalated in 1951, Dr. Katz enlisted in the U.S. Army, where he ran a MASH unit. With his colleagues, he developed a protocol for diagnosing and treating hemorrhagic fever (Barbero, Katz, & Kraus, 1953; Katz, Leedham, & Kessler, 1952). The disease had become epidemic among the troops; when the mortality rate dropped from 10% to 1%, Dr. Katz's work received national acclaim.

Upon returning from the war, Dr. Katz joined the faculty at Western Reserve, where he held joint appointments in Medicine and Preventative
Medicine and re-established his career commitment to research. A colleague there recommended him to Dr. Austin Chinn, the Medical Director at the Benjamin Rose Hospital, to lead a research study on the effects of adding vitamins to older adults’ diets. Dr. Katz demurred because he felt his lack of experience with older patients did not qualify him for the job (Katz, 2012). After 6 months spent in seeing older patients and studying health care for the aged people, Dr. Katz accepted the position—thankfully for the field of aging. However, his work went far beyond studying the effects of vitamins. He designed the “Multidisciplinary Study of Illness and Aged Persons” and set out to answer the question of how to evaluate the effects of a treatment or therapy on older people. Dr. Chinn’s quest was to find “...a real yardstick to measure how older people differ from younger ones, even healthy older persons” (Johnson, 1996, p. 147). As the multidisciplinary team focused their efforts on this question, Dr. Katz credited a friend with suggesting what he needed was a tool to measure and predict function (Katz, 2004).

Early in his tenure at the hospital, Dr. Katz’s work was distinguished by a movement away from the medical model of care toward a more balanced multidisciplinary and holistic approach. This work eventually led him to become a staunch advocate for evidence-based policy development, intended to make policies affecting older adults’ access to care and the delivery of care to them more rational. Dr. Katz’s national platform for this policy approach came with his appointment as Chair of the Institute of Medicine’s Committee on Nursing Home Regulation (1986). The committee offered evidence-based recommendations to improve nursing home regulation that were incorporated into the Omnibus Budget Reconciliation Act of 1987 (OBRA-87). This brought about a dramatic change in the manner in which nursing homes were regulated, as well as improvements including assessing standardized resident outcomes, developing individualized care plans, and formulating quality of care indicators.

Dr. Katz’s career in geriatric medicine is closely entwined with the Benjamin Rose Institute on Aging. It began in the 1950s with his early work as the Supervisor of Research at the Benjamin Rose Hospital and ended with his last twenty-two years (1989–2011) as the Institute’s Distinguished Scholar; in 2007, the Katz Policy Institute of Benjamin Rose was established in his honor. Over the latter period, the authors of this article had the enormous privilege of benefiting from his wisdom and grace and now have the privilege of chronicling the broad scope of his contributions to the field of aging.

**ADLs: A Standardized Measure of Function in Studies of Illness and the Aged People**

The Benjamin Rose Hospital was established through a partnership between the Benjamin Rose Institute and University Hospitals of Cleveland as a prototypical rehabilitation hospital for long-term care of the elderly adults. In the 1950s, there were no scientifically developed guidelines for chronic care nor was there a body of empirical evidence about the course of chronic illness and the effectiveness of specific treatments. The multidisciplinary team of physicians, nurses, social workers, and physical and occupational therapists at the hospital made it their mission to carry out thorough patient assessments and document each patient’s progress. They used data on outcomes to determine what treatments worked for whom and applied this knowledge to improve clinical decision making.

Development of the index of ADLs was based on a study of 64 hip fracture patients, admitted to the hospital over an 18-month period, during which comprehensive data were recorded on their physical, psychological, and social characteristics (Staff of the Benjamin Rose Hospital, 1959). With the goal of restoring patients to as much independent functioning as possible, the team made a thorough study of each patient’s activity status pattern using a graded index to record functional independence or dependence in bathing, dressing, toileting and continence, transferring, and feeding/eating. The criteria for independence were clearly explicated; for example, dressing was evaluated as independent if the patient could get all the clothes from the closet or drawer, put them on, and fasten them without supervision, direction, or active assistance.

The researchers reported finding a hierarchical pattern of progression in ADLs, with bathing being the most complex task and feeding the least. Thus, patients who functioned best could independently bathe, dress, transfer, toilet, control continence, and feed themselves. This single measure using a graded scale was regarded by the developers as a more specific and standardized means to describe changes in patient status over time, compare changes in patients receiving different treatments,
and teach nursing and medical students objective ways to evaluate functional status and the course of chronic illnesses. The researchers provided a theoretical basis for the measure by drawing upon theories of child development (Katz et al., 1963). They noted that the order of recovery of function for disabled elderly patients paralleled the development of primary functions in children. Thus, they concluded that the index of ADLs was based on primary biological and psychosocial functions that reflected the adequacy of neurological and locomotor responses.

In a 1970 article published in The Gerontologist, Dr. Katz and his colleagues charted their progress in improving the index of ADLs (Katz, Downs, Cash, & Grotz, 1970). By this time, with more than 10 years of data from Benjamin Rose Hospital patients with hip fractures and strokes, they were able to report on factors associated with poorer prognoses. More advanced age and comorbidities were consistently associated with poorer outcomes, with little likelihood of recovery for patients with these conditions who had not shown any recovery in the first 2 years.

To emphasize the importance of multidisciplinary coordinated care between hospital and home (currently referred to as better management of care transitions), they also included findings in this article from a study that used the index to assess and monitor patients following hospital discharge. The research study, in which Benjamin Rose Hospital staff worked in collaboration with nurses from the Cleveland Visiting Nurse Association, showed that patients receiving home care posthospital discharge had lower rates of deterioration in ADLs compared with those who did not (22% and 40%, respectively). The authors concluded by advocating for more research on well-specified therapeutic interventions for older persons with chronic illnesses using clear eligibility criteria and quantitative methods.

Although the index of ADLs has unquestionably made a monumental contribution to the study of chronic illness and the aged people, later researchers have refined it as science has evolved. One of the most significant of these efforts, published by Lawton and Brody (1969), expanded the range of activities to include instrumental activities of daily living (IADLs), which are more complex than ADLs and critical for older adults to continue living independently. Their original scale covered eight domains for women: using the telephone, shopping, preparing food, housekeeping, doing laundry, using transportation, taking medications, and handling finances. (Housekeeping, laundry, and food preparation were excluded for men.) Together, the ADL and IADL scales continue to serve as the primary basis for the functional assessment of older adults in national public health surveys and in clinical settings, for example, hospital discharge planning.

Other issues with the index of ADLs that have been addressed by later researchers are the manner in which ADLs are conceptualized, that is, as a uni- or multidimensional construct (Spector & Fleishman, 1998), the continued lack of consensus about how to measure ADL disabilities (Wiener, Hanley, Clark, & Van Nostrand, 1990), and the need for measures that expand the range of disabilities beyond the narrow a set of functional activities covered by the original ADLs (Albert, Bear-Lehman, & Burkhardt, 2009). As recounted to this article’s authors, Dr. Katz fully expected future scholars and researchers to extend his thinking about measures of function in the elderly adults and significantly advance our understanding of chronic disease and effective health treatments as new tools and technology became available. At the height of his career, mapping the human genome was years away, as were effective treatments to prevent chronic conditions. Thus, 40 years ago, Dr. Katz wrote that the goal of rehabilitation services was “secondary prevention” to slow the course of deterioration in chronic illness and prevent complications; preventing the onset of chronic disease was seen at that time as an unreachable goal (Katz, Ford, Downs, Adams, & Rusby, 1972).

**Management of Chronic Illness in the Community**

Dr. Katz had a keen interest in the organization and delivery of long-term care services for chronically ill elderly persons. He recognized early on that care for chronic illness was distinct from acute care because chronic illnesses evolve from many causes, have multiple manifestations, and require a variety of services over extended time periods (Stroud, Katz, & Gooding, 1985). As a result, chronically ill and disabled persons use a disproportionate share of the nation’s health service resources. Many of his ideas about long-term care were prescient, such as the need for care coordination and the strategic importance of primary care physicians, which are currently playing a key role in the restructuring of state Medicaid programs and in designing health
He and his colleagues asserted that persons with chronic diseases living at home required care from interdisciplinary teams that can carry out a coordinated process of initial assessment, set and modify goals, deliver therapeutic and restorative services, conduct reassessments, and provide follow-up monitoring (Katz et al., 1972). They advocated for the use of public health nurses as one approach to coordinating care among home, hospital, and the patient’s primary care physician. In their research studies on home care following hospital discharge, these nurses served as long-term care planners, information and referral specialists, and care coordinators, in addition to providing skilled nursing services.

Findings from their research studies showed that home care posthospital discharge had more benefits in terms of restored functioning for younger and less disabled elderly adults compared with older and more disabled elderly adults (Ford, Katz, Downs, & Adams, 1971; Katz et al., 1972). The latter group, they concluded, is better served with less costly services from homemakers, day care centers, and companions, rather than more costly hospital and rehabilitation services. Based on the strength of their research findings about the benefits of paraprofessional homemaking and personal care services for posthospitalized elderly patients, the Benjamin Rose Institute established its own Home Aide Department in 1968 and began the Senior Companion Program in 1980.

The attention Dr. Katz and his colleagues paid to service benefits and relative costs at that time is noteworthy. They argued that social and psychological supports with decent living conditions at home were a more humane and a less costly alternative to nursing home care as long as there was ready access to professional services should a medical need arise (Katz et al., 1972). They also advised that the index of ADLs should be used to assess service needs in order to avoid the under- and overuse of services that could result in unmet needs or inappropriate dependency. They urged policy changes that would establish service entry, use, and exit criteria in order to improve care delivery and make more rational use of Medicare and Medicaid funds. Using evidence from their research findings, they proposed three categories of eligibility criteria for long-term care services: (a) Older adults with potential for full or partial recovery of function should have access to organized programs in skilled care settings (i.e., rehabilitation and chronic care hospitals); (b) Those with little or no potential for recovery of function should have access to maintenance and support programs (i.e., home care and nursing homes); (c) Those at the end of life should have access to support services in anticipation of death (Katz et al., 1972).

Dr. Katz continued to refine his thinking about long-term care for chronically ill elderly persons when he joined the College of Medicine at Michigan State University in 1971. There he undertook a 4-year demonstration and evaluation project of a Chronic Disease Module using interdisciplinary teams and specially trained visiting nurses to deliver home care services (Papsidero, Katz, Kroger, & Akpom, 1979). The premise of the project was his belief that existing health services provide discontinuous and fragmented care to the chronically ill living in the community, a contention that to this day describes the experience of health care for many older adults with chronic illnesses.

The module included a number of core features that now are commonly regarded as central to quality long-term care. It emphasized the standardized collection of uniform information on patient functioning embedded in a comprehensive assessment covering multiple domains (physical, psychological, social, and economic). The focus of the data analysis was on patient outcomes and identifying the predictors of services that were most efficacious for specific types of patients. The data were also regarded as vital to inform and improve clinical judgments. In addition, data on service design, staffing, delivery methods, and costs were combined with patient outcome data in order to formulate evidence-based policy recommendations about the appropriate target population, service eligibility criteria, financing mechanisms, and regulation. Especially noteworthy, the demonstration project focused on patient-centered care and quality of life, not the structure and process of service delivery. As such, it presaged the current emphasis on person-centered long-term care and efforts to broaden our thinking beyond medical care outcomes to more global indicators of quality of life.

Managing Chronic Illness in Residential Care Settings

While Dr. Katz was conducting research at the Benjamin Rose Hospital in the 1950s, he began a
lifelong collaborative relationship with Dr. Morris Stroud, the medical director of another Cleveland-area rehabilitation hospital. They had a mutual interest in undertaking research studies to determine empirically whether rehabilitation produced measurable improvement in function. For the next 30 years, they engaged in a series of projects toward this end involving longitudinal epidemiological studies and service experiments (Katz & Stroud, 1989; Stroud et al., 1985).

Both witnessed serious shortcomings in the management and operation of hospital rehabilitation, such as fragmented care between the rehabilitation unit and floor units, specialists who worked independently rather than coordinating care, patients being kept in the hospital when their prognoses for recovery were poor, and a lack of follow-up monitoring of the patients’ progress postdischarge. Under their guidance and direction, patients received a comprehensive assessment prior to admission, during the rehabilitation period, and quarterly at home for 2 years postdischarge. The service experiments they undertook led to meaningful changes in the organization and delivery of rehabilitation care that deserve thoughtful reconsideration in light of current health care reform efforts emphasizing person centeredness and care coordination.

One of their innovations was to establish a liaison process for all care settings (e.g., primary care office, rehabilitation setting, and acute care hospital) with regularly scheduled meetings and a single transfer form shared by all care providers. Current advances in communication technology and shared electronic medical records now make it easier to facilitate care coordination across settings, in contrast to the in-person meetings and transfer of paper forms that characterized health care during the period of their collaboration. Nevertheless, there are still obstacles to current attempts to coordinate care using shared information, including patients’ rights to privacy, institutional legal liabilities, incompatible information platforms, and technology costs. Even as we work to overcome these obstacles, efforts to coordinate care and transfers across settings continue to be complicated by the same human factors documented by Drs Katz and Stroud in their collaborative studies. Some of these included communication problems encountered by interdisciplinary teams lacking a common language about function, competition for resources and prestige, and leadership struggles.

In an effort to remedy the lack of a common language about function, Drs Katz and Stroud participated in federally supported initiatives to develop classification systems for research, clinical, and educational use: Patient Classification for Long-Term Care User’s Manual (Jones, McNitt, McKnight, & U.S. Health Resources Administration, 1973) and the Long-Term Health Care Minimum Data Set (U.S. National Committee on Vital and Health Statistics Technical Consultant Panel on the Long-Term Health Care Data Set, 1980). These products, most notably the minimum data set, were essential to the successful work of the Institute of Medicine (IoM) committee on nursing home reform and the passage of Omnibus Budget Reconciliation Act in 1987 (OBRA-87), which represented a new era of policy making in long-term care (Milbank Memorial Fund, 2003, p. 12).

A second important innovation was their shift in emphasis from patient services to “the patient-family constellation” as the focus of care, documented in their book chapter that explicated ways to improve rehabilitation (Stroud et al., 1985, p. 155). Early on, these investigators recognized the critical importance of the older patient’s family members as facilitators of and intermediaries in the older patient’s use of health care and as care managers and providers. The health care teams actively and systematically involved the patient and family members in care planning and decision making. Their empathy and concern for patients and families are evident in the following passage: “Waiting time is often excessive for both patient and family, and the absence from work is costly. Therefore, more effort must be made to meet the needs of the patient and family when arranging schedules. Wherever possible, scheduling should be negotiated. At the very least, the need to wait should be explained. Home care, if possible, is preferable to routine clinic visits.” (Stroud et al., 1985, p. 158). This focus on the patient-family constellation suggests that as health care reform unfolds in the coming years, careful attention needs to be paid to the design of health care services and systems that are cognizant of and responsive to the needs, concerns, and preferences of patients’ families, particularly at times of care transitions (Family Caregiver Alliance, 2010).

**Overhaul of Nursing Home Regulation**

Beginning in 1965, Dr. Katz was actively involved in many of the working committees of the National
Center for Health Services Research, and he was appointed to the National Academy of Sciences’ IoM in 1978. In 1983, he was asked to chair IoM’s Committee on Nursing Home Regulation, which was established to formulate recommendations to improve the quality of care in nursing homes. This landmark event was preceded by a number of national scandals about nursing home care and publication of the award-winning book, Tender Loving Greed, by Mary Adelaide Mendelson (1974), which detailed how lucrative the nursing home industry had become by exploiting older persons through fraud, swindles, and corruption. Additionally, in 1982, the Health Care Financing Administration (now the Centers for Medicare and Medicaid Services) proposed changes in nursing home certification procedures that became very controversial, prompting calls for the study of nursing home regulation undertaken by the committee.

Dr. Katz skillfully led this committee for 2 years and stood by his principle that the recommendations made would be based as much as possible on scientific evidence, arguing that effective nursing home regulation and more rational public policy required the necessary empirical data. However, he acknowledged that a number of committee’s recommendations rested on the professional judgment of its members (Institute of Medicine, Committee on Nursing Home Regulation, 1986, p. ix). Following lengthy deliberations, public hearings, reviews of states’ best practices for regulation, and preparation of commissioned articles on nursing home quality assurance, the committee members unanimously endorsed the final report proposing an extensive series of comprehensive and innovative recommendations to improve nursing home regulation, the quality of nursing home care, and residents’ rights and quality of life.

The recommendations of the Committee on Nursing Home Regulation were incorporated into OBRA-87, commonly known as the Nursing Home Reform Act. The passage of OBRA-87 led to a sweeping set of reforms in nursing home regulation that shifted the regulatory focus from paper compliance with standards to a focus on residents’ lives as lived in nursing homes. The legislation simultaneously changed the standards for regulation, the inspection process and determination of compliance with the standards, and the enforcement system for failure to comply, making all three components resident and outcome focused (Milbank Memorial Fund, 2003, p. 12). The care actually provided to residents was now observed during the survey process and sanctions were put in place for unacceptable resident outcomes, such as injury from the use of physical restraints.

Undoubtedly, Dr. Katz was especially gratified by acceptance of the recommendation to have residents’ functional, medical, social, and psychological needs individually determined and met through uniform assessment and regular reassessments conducted by specially trained nurses. The requirement for a standardized comprehensive resident assessment led to the development of the Resident Assessment Instrument-Minimum Data Set (RAI/MDS) that was mandated in 1991 (Hawes et al., 1997). Its designers were an international group of researchers and clinicians who facilitated the adoption of the RAI/MDS by other nations. A related recommendation that was implemented mandated care planning by interdisciplinary teams using the assessment data, with the process open to participation by residents and their families (Institute of Medicine, Committee on Nursing Home Regulation, 1986). The content of these recommendations can be traced back to Dr. Katz’s earlier experiences with the long-term care of patients in rehabilitation hospitals and his efforts to improve patient outcomes and the quality of their care using standardized functional assessment data. In addition to its use for resident assessment and care planning, the RAI/MDS became the basis for creating quality indicators to evaluate care, develop quality improvement programs, guide the regulatory process, and generate Resource Utilization Group scores for reimbursement purposes. The RAI/MDS has been criticized for failing to assess quality of life and to mandate resident interviews and for allowing nursing home providers to game the system by manipulating RUG scores, but subsequent versions have addressed some of these shortcomings (Rahman & Applebaum, 2009). Regardless of its limitations and deficiencies, the uniform resident assessment, along with other changes brought about by OBRA-87, significantly altered care delivery, regulation, and reimbursement for nursing homes in this nation and internationally.

**Expected Duration of Functional Well-Being**

By the 1980s, demographic trends of greater longevity, lower mortality, and disproportionate growth of the 65 and over population were eminently clear. The approach to assessing health and well-being of the older population changed from a focus on survival or mortality rates to measurement of quality of life in later years. Dr.
Katz’s thinking about functional status measurement for informing prognoses for chronic illness expanded to developing an indicator of quality of life based on the possibility of significant portions of later life remaining disability free. In 1983, Dr. Katz and his colleagues published another seminal article that introduced the concept of “active life expectancy,” defined as the period of life free of disability in ADLs (Katz et al., 1983). Their research used life table analysis to investigate increments and decrements in ADL functions among a number of subpopulations of noninstitutionalized elderly persons living in Massachusetts. Based on findings from their analyses, they projected the remaining years of functional well-being for different age groups. The findings showed that active life expectancy decreased from 10 years for those aged 65–70 to 2.9 years for persons aged 85 and older. Moreover, active life expectancy was shorter for those who were poor, and women had a longer period of expected dependence than men.

The development of the active life expectancy construct provided an important indicator of population health and an alternative to the mortality rate. The originators also underscored its utility for targeting high-risk populations for preventive health care and health promotion programs, thereby extending their years of active living and compressing morbidity at the end of life. Later researchers refined the underlying assumptions and analytic approach to investigate active life expectancy (Manton & Land, 2000; Rogers, Rogers, & Branch, 1989), but the concept itself continues to be widely viewed as a groundbreaking advancement in epidemiological studies of the health of older populations.

Conclusions

As a legacy article, our objective was to recount the myriad contributions Dr. Sidney Katz made to gerontology and geriatrics over the course of his decades-long career as a clinician, researcher, policymaker, advocate, teacher, mentor, and widely recognized leader in the field. Although he received many awards for his accomplishments, including the Maxwell A. Pollack Award (1993) and the Donald P. Kent Award (1995) from the Gerontological Society of America, the one of which he was most proud was the Lifetime of Caring Award. When it was given to him in 2001 by the American Geriatrics Society’s Foundation for Health in Aging, he was only the second person to receive the award, following former President Jimmy Carter. Dr. Katz most wanted to be remembered as a caring person who did not seek greatness or acclaim, but used his intellect and remarkable skills and abilities to improve the lives of as many people as he could.

Clearly, Dr. Katz had unprecedented insight into ways to better design and deliver health and social services for chronically ill persons. The concepts he advanced, beginning in the 1950s with functional status, standardized assessment, and multidisciplinary teams, were the foundation upon which he built to develop the concepts of care coordination, the patient-family constellation, regulation of long-term care focused on person-centered outcomes, active life expectancy, and quality indicators for long-term care services. He developed these concepts, which have withstood the test of time, during an era when information-gathering and analytic tools were relatively limited and by today’s standards archaic. In a book written about him by his daughter, she recounts how as a child she would watch him spend evenings hand-sorting slips of paper with patient information on them to create meaningful categories and hand-tallying the results (Katz, 2012). His quest for scientific evidence as an informational base for clinical- and policy-related decision making drove his life-long career in health services research.

In this era of electronic medical records and health information exchanges, researchers now can access an enormous abundance of data across care settings and patient populations. We continue to move forward with new technologies in hopes of improving care delivery and care outcomes. Dr. Katz undoubtedly would be amazed by the advanced diagnostic and other tools at the disposal of today’s clinicians and researchers; however, he would still caution that they are only as valuable as the interdisciplinary planning and collaborative thoughtfulness that lies behind their application.

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