

Defining the Burden of Skin Disease in the United States—A Historical Perspective

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Burden is an ancient biblical term, denoting a heavy load or fate, that I found convenient to use as a title of a 1975 report to encompass the findings of prevalence, morbidity, disability, and social costs of dermatologic disease, in the first US Health and Nutrition Examination Survey of 1971 to 1974 (HANES) (Johnson, 1978). In the advent of HANES, because the impact of disease in the US population was measured in terms of mortality, data derived from death certificates, the importance of skin disease was considered to be trivial. After HANES, to serve the information needs of planners and payers for health services, assessments began to include attendant morbidity and altered functional status of patients, and the consumption of goods and services for their care. Nevertheless, such assessments have not been made on the basis of data gathered from examination of a large representative sample of the US population of ages 1 to 74, nor with the scientific or epidemiologic rigor of HANES.

History of the Inclusion of a Dermatologic Component in HANES

The opportunity to establish, for the first time, reliable and scientifically valid estimates of the burden of skin disease in the United States came to me in Hiroshima, Japan. There, in 1966 at the US National Academy of Sciences–Japanese National Institute of Health Atomic Bomb Casualty Commission (ABCC), Arthur McDowell of the US National Center for Health Statistics (NCHS) visited ABCC as a consultant and gave a seminar on biostatistical and epidemiologic planning and procedures of health examination surveys of the US population that had been used in two prior NCHS surveys, a third was in progress. Observations about the skin were not included in the first two, and the third only noted the presence or absence of acne and the number of nevi.

During his visit, Mr McDowell reviewed my first and ongoing research in the epidemiology of skin cancer and accelerated aging in a sample of 15,000 A-bomb survivors and controls. He seemed amused to meet a dermatologist who was performing an epidemiologic study and who was

as strict as he would be about its proper conduct. The latter reflected the training and guidance I had received from outstanding senior ABCC staff.

When he mentioned that the next health examination survey was scheduled to begin in 1971, I urged him to consider the great importance of including a comprehensive skin examination, and we reviewed the technical and logistic problems involved in realizing my request. Convinced of the gain for dermatology of this undertaking, I promised to be responsible for many things: the design and testing of the examination forms and procedures, providing an expanded ICD code, recruiting and training examiners in an assessment of the extent and morbidity of skin conditions to work at 65 field stations in the United States, and securing pathology services for handling scrapings and biopsies. It was clearly a study of such complexity and cost that only the federal government could afford it.

I left Japan in 1967 to join Rudolf Baer, MD, chair of the Department of Dermatology at NYU Skin and Cancer Unit at the precise moment that the AAD's Joint Committee on Planning for Dermatology was beginning, with the urging of Philip Anderson, MD, to plan its National Program for Dermatology. I was selected as its secretary and chair of the data collection unit.

Dr Baer, chair of the Joint Committee, shared my excitement about the inclusion of a dermatologic component in the next NCHS health examination survey. With the strong and broad support of Drs Baer and Anderson; of the President of the Academy, Clarence Livingood, MD; and of all academic chairs of departments of dermatology and their residents and with NYU's diagnostic codes developed by Alfred Kopf, MD, all of my grand promises to NCHS could be met.

All 65 stations were staffed by over 100 dermatologists/examiners, mainly senior dermatology residents who were prepared for their assignment at annual meetings of the Academy by David Ramsay, MD, and myself. The comprehensive screening examination demanded for HANES bore only a slight resemblance to the usual encounter in the dermatology clinic; so many observations and variations had to be noted and recorded as well as diagnoses. Dr Ramsay or I would meet with the examiners on site to reinforce their training. The NYU Code of Skin Diseases worked well. At the completion of the survey I had reviewed representative samplings of the 20,637 examinations to

Abbreviations: ABCC, Atomic Bomb Casualty Commission; HANES, Health and Nutrition Examination Survey; NCHS, National Center for Health Statistics

ensure consistency with the examination protocol and resolved the diagnoses of skin cancer and dermatophytoses on the basis of subsequent findings of biopsy and laboratory determinations of fungus.

HANES Findings (1971–1974)

Skin pathology Nearly one-third (312.4 per 1000 population), or an estimated 60 million of the US population age 1 to 74 y, had some skin pathology: one or more significant conditions that called for evaluation by a physician.

The prevalence of significant skin pathology increased rapidly with age from 14.2% at age 1 to 5 y to 36.5% at age 12 to 17 and 36.5% at age 18 to 24 (Fig 1). The prevalence continues to increase with advancing age, reflecting cumulative increases in such diagnoses as psoriasis and vitiligo and the accelerated appearance of malignant and benign tumors, as well as actinic and seborrheic keratoses.

Among the specific types of skin pathology, the most prevalent were diseases of sebaceous glands, dermatophytoses, tumors (malignant and benign), seborrheic dermatitis, atopic dermatitis/eczema, contact dermatitis, and ichthyosis/keratosis (Fig 2).

Occupational exposure Nearly one-fourth (23.9%) of adults 18 to 74 y of age with significant skin pathology

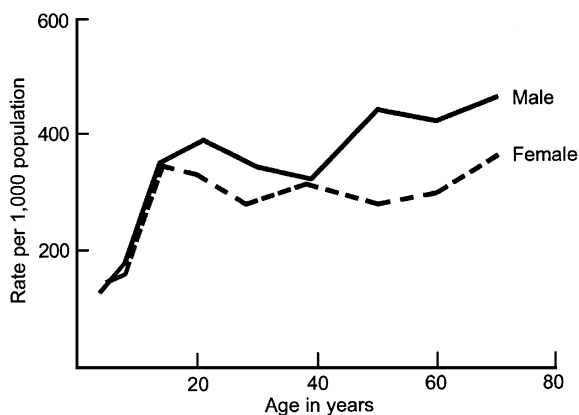


Figure 1
Prevalence rates for significant skin pathology among persons 1 to 74 y by age and sex: United States 1971 to 1974.

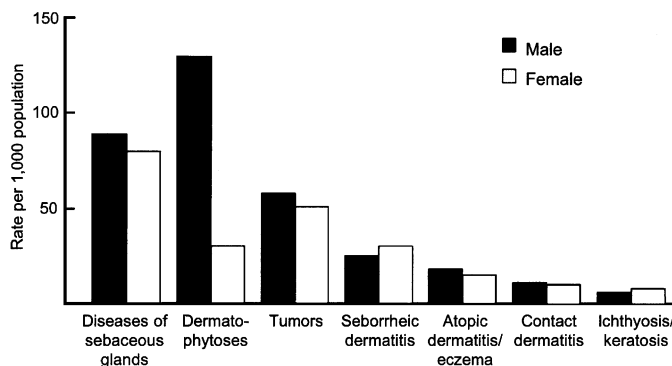


Figure 2
Prevalence rates for the seven leading types of skin pathology among persons 1 to 74 y of age, by sex: United States 1971 to 1974.

indicated exposure in the work place to chemicals, fumes, vapors, oils, or insecticide or to prolonged immersion of the hands and feet. Occupational exposure was twice as high among men (32.4%) compared to women (14.4%); among both sexes the rates drop off at age 65 to 74.

In addition to gathering data about normal variations and the presence of benign lesions as well as pathology, one-third of the examination form focused on specific diagnosis and details about the atopic individual, the psoriatic, for example. But of greater interest for a consideration of the burden of the problem is that one-third of the form gathered data about the impact of the dermatologic diagnosis on the individual and his or her psyche as well as soma and how it troubled him or her and interfered with function, livelihood, and social interactions. We also asked the examiner to weigh the handicap and, further, to assess the problem from the standpoint of care. Was the patient receiving the best care for that problem and if not, why not? Was the patient or his physician unaware that there was helpful treatment—or was the care too distant, the treatment too expensive?

Examinee's concern There was also in this section a focus on the examinee's concern, their complaints, and their perception of their problem. Some 11.8% or an estimated 22.9 million of the US population 1 to 74 y of age had one or more conditions about which they complained or expressed concern. Most (96%) complained about a specific condition affecting a specific part of the body: their hands (9%) and feet (16%) and, for 75%, their face or neck or other areas of the body.

Persons with significant skin pathology diagnosed in the survey examination were most likely to express concern if the condition were psoriasis (69%), atopic dermatitis (59%), contact dermatitis (47%), malignant tumors (34%), and diseases of the sebaceous glands (35%).

Personal Burden

How then did these complaints translate to a *personal burden*?

- A *limitation of activity* owing to the cutaneous diagnosis was noted by 9% of persons having significant skin pathology with one-third reporting the limitation to be moderate to severe. Conditions involving the hands and the feet are more likely to limit activity (15%) than those of the face (8%) or other parts of the body.
- A *social handicap* was cited by about one-third (33%) with skin conditions, and of those socially handicapped the percentage is substantially greater among women (34%) than among men (25%).
- *Disfigurement* was a complaint of more than two-thirds (68.1%) of those expressing concern and the complaint was in turn rated by the dermatologists/examiners: 48% were considered minimal, 20% were moderate, and severe was highest among youths 12 to 17 y of age and in older adults 55 to 74 y of age.
- *Discomfort* among examinees with skin complaints was described as a burning sensation or pain by 22.8%, as pruritus by 45.4%, and as physical limitation of motion by 6%.

Nearly all (89%) of persons who considered their condition a social handicap were also rated as disfigured by the dermatologists/examiners. Agreement between the examiner's rating of disfigurement and the individual's reporting a handicap to employment or housework was 80%.

Adequacy of Dermatologic Care

Rating the adequacy of dermatologic care received by persons with skin complaints, the examiners believed that only 19% had received adequate care. Of the remaining 81% who had not, nearly all (94%), in the judgment of the dermatologists/examiners, would improve with more expert care.

In summary, HANES findings soundly refuted the widely held opinion that skin disease was a trivial contributor to illness, disability, and morbidity in the US population. HANES findings greatly exceeded the intuitive estimates of dermatologists in the magnitude of skin disease in the United States 60 million, one-third of the US population with skin pathology. Further, among the afflicted, more than 24 million coping with employment and social handicaps, discomfort, and disfigurement, only 19% were receiving care of adequate quality. HANES provided scientifically derived and evidence-based data.

After HANES Almost 30 y have passed since HANES was undertaken, and a HANES redux in all its comprehensive and expensive finery is highly unlikely. Since the early 1970s, the US population has grown from 193 million to 281 million. Since 1971 to 1974, substantial changes have occurred in the ethnic distribution of the US population, primarily owing to immigration (U.S. Census Bureau, 2001). For example, Hispanics are now the largest minority group, exceeding 35 million. In two of our largest cities, Los Angeles and New York, the "minorities" are becoming majorities. Most of the population growth in the US has occurred in cohorts of younger ages. Thus, the HANES-documented prevalence rates in older persons (65 y and older) have not been confounded by substantial new additions and can be reliably extrapolated to the current older population. For example, in the HANES 65- to 74-y age group, the highest prevalence rates were for skin tumors (18.4%), all malignant skin cancers (3.6%), basal cell carcinoma (2%), and precancerous including actinic keratoses (8%). By the year 2000, the number of persons age 65 to 74 in the United States had increased by 5.6 million. In 2000, persons 75 y and older (a group not included in HANES) numbered 16.6 million; the HANES data extrapolated rate of malignant cancers for this group is 6%. The total estimated numbers of *additional* persons with malignant skin cancer is 204,000 in the 65- to 74-y age group and

996,000 for persons 75 y and older. The steep increases reflect the aging of America: 35 million persons 65 y or older, with 1 in 8 now more than 80 y of age.

Nevertheless, a repeat survey in 2003 would be likely to discover new and additional dermatologic morbidity related to the leading causes of illness and death in the US population: cardiovascular disease (42%) and cancer (23%). Immunosuppression, cardiovascular drugs, and chemotherapy have attendant dermatologic morbidity. Also, HANES preceded the epidemic in the United States of HIV-AIDS. Further, since HANES predated the ubiquitous implementation of managed care, its estimates on access to dermatologic care and the quality of care received can serve only as a 1971 to 1974 baseline.

In the past 30 y, US dermatology has made an enormous advance in biomedical science and technology. To what extent derived clinical benefits are accessible in the dermatologic care of the US population, particularly to 40 to 60 million un- and underinsured, is a key question in assessing the burden of skin disease.

I believe that the purpose of a new initiative on the burden of skin disease, aside from updating the magnitude of the problem and identifying the most burdened, is to identify obstacles to mitigating the burden. In 1969 the National Program for Dermatology sought "to conquer disability due to skin disease through patient service, education, and research" (American Academy of Dermatology, 1969). In 2003, we have, within universal reach, powerful communications technologies available that can improve with great effect and efficiency the pattern and quality of care of the system of delivering care to those who bear the burden of skin disease.

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