Justice and Health Care in the Rheumatic Diseases

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Abstract Coping with a chronic disease is a formidable challenge. Owing to the disabling consequences of their underlying conditions, individuals who suffer with a chronic rheumatic disease have especially daunting lives with their existence often dominated by their health-related needs. Due to the high prevalence, the demographic distribution, indeed the very nature of the rheumatic diseases, too many sufferers of these conditions in our society remain disenfranchised with respect to their access to health care. Those who come from already disadvantaged socioeconomic circumstances face particularly difficult challenges. Rheumatologists and their allied health professionals, therefore, have a moral obligation to ensure greater fairness to their patients—those already compromised by the natural lottery that gave them their disease. To enhance the appreciation of this problem and to motivate the rheumatic disease community, we attempt to identify those variables that create the need for and imperil access to medical care for the rheumatic diseases. The implications of these observations are then explored from the ethical perspective of *justice*. We conclude with suggestions as to how to change the health care system to address these problems.

Key words rheumatic disease · disability · access to health care · justice

The problem

The diseases

Arthritis and the rheumatic diseases are the most prevalent chronic conditions affecting Americans [1–3]. Currently, more than 15% of the US population suffer from one of these diseases, a prevalence that will only increase with the aging of society. More than 100 diseases and conditions have been described. The implications of these disorders are enormous and can be measured in several ways [4]. Some measures translate readily into economic terms such as cost of medical care or lost earnings. Other consequences, which are more patient and family centered in their orientation, are also profound and include the impact of the disease on functional capacity, quality of life, mental health, or premature death. Furthermore, there are the symptoms that accompany these conditions, namely, chronic pain and physical impairment. Because the burden of rheumatic illness is disproportionately assumed by certain segments of our society, specifically those African Americans of low socioeconomic and educational standing, women, and the elderly, these conditions present formidable practical as well as ethical challenges for the health care system and society at large.

Disability

To the individual sufferer, a rheumatic disease with its myriad clinical manifestations not only produces widespread symptoms and organ system dysfunction but often result in severe functional incapacity and disability. Indeed, as a group, the rheumatic diseases are the leading cause of disability in our society [5]. Extensive epidemiologic investigation confirmed that these conditions limit the major activity of nearly 3% of the entire US population (7 million persons), nearly 1 out of 5 persons who suffer from arthritis and as a cause of work-related disability, arthritis trails only that of heart disease.

In addition, quality of life is consistently worse for individuals who are arthritis sufferers whether those measures are healthy days in the past 30 days, days without

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severe pain, “ability days” (i.e., days without activity limitation), or days without difficulty in performing personal care activities. Affected individuals report 2 to 3 times more difficulty in walking and experience more specific functional limitations. Their rheumatic disease is a major reason for nursing home placement and is an independent predictor of increased mortality.

Education, employment, and income

We next consider education, employment, and income together because they seem to act synergistically, perhaps as markers for poverty and as important determinants of the consequences of suffering from one of the rheumatic diseases [6].

With respect to the influence of income and education, an analysis utilizing the Health and Nutrition Examination Survey (HANES) showed that individuals from lower income strata and educational attainment have higher rates of activity restriction, more change in job status, and higher rates of disability as compared to higher income earners [7]. Other sources also showed that poorer, less educated individuals have higher rates of arthritis than those who are better educated and have more financial resources. Indeed, numerous sources have confirmed the observation that rheumatic diseases are more likely to arise in those less economically advantaged and the overall outcomes experienced by these individuals are also worse [8–10]. The reason for this association, although not fully understood, may lie in the type of work available to such individuals.

Employment, specifically the nature of the work performed, is an important determinant of medical care in the rheumatic diseases. Indeed, in the arthritis sufferer, the patient's occupation may exert its influence at a far more fundamental level than simply its role in providing income and a means for the procurement of medical insurance. In such individuals, the type of work, specifically poorly compensated jobs which place higher demands on the joints, appear to constitute “high risk” occupations with respect to the development of arthritis [9]. Work of a repetitious nature requiring heavy physical exertion (and often dangerous working conditions) correlates with the development of arthritis. Back and knee problems predominate, although activities such as standing, bending, walking long distances, lifting, and moving heavy objects also seem to increase the risk of osteoarthritis, mainly of the hip.

Sociocultural considerations

The problem of access is further exacerbated by other social and cultural determinants of disparity in health care delivery. The general epidemiologic patterns of those diseases such as female predominance, disease-specific age of onset, and racial distributions have been known for decades. The interplay between the demography of the rheumatic diseases and the functional consequences of these conditions are not yet widely appreciated. For instance, among Caucasians, arthritis is the most common chronic condition and the second leading cause of activity

limitation. However, despite similar rates of disease, African Americans appear to suffer even greater functional consequences [2, 11, 12]. For instance, amongst African Americans, arthritis is the third most common condition but the leading cause of activity limitation. Other disenfranchised groups, such as Hispanics, American Indians, Alaska natives, and Asian and Pacific Islanders, also have variable corresponding rates of limitation, although in all demographic groups, the prevalence of such disease and its attendant disability is high.

Racial influences may also work in other ways. Health beliefs, that is, attitudes, values, and knowledge concerning health care, also provide an additional context for understanding how demographic factors might influence access to medical care. A desire to engage in self-healing and wellness promotion or the use of folkloric remedies may be noneconomic barriers to the use of conventional medical services [13]. Another example of how such influences may influence treatment choices is a recently reported analysis of hip and knee pain [14]. In this study of African Americans and Caucasians, subjects were more likely to have sought diagnosis and treatment for hip and knee symptoms when they were acquainted with members of their own social network who had experienced successful outcomes after treatment for similar conditions. Thus, African Americans (in contrast to Caucasians) who knew fewer individuals who have undergone such treatment (including joint replacement surgery), were less likely to perceive treatment as beneficial and were less likely to seek medical care. Such cultural influences, acting in concert with the aforementioned financial and disease-related factors, represent formidable impediments to accessing medical care.

Utilization of treatments

Examined broadly, there is now ample evidence from the literature confirming in a wide range of medical conditions that health care delivery has been covertly and inequitably distributed on the basis of such properties as race and gender. Regrettably, such disparities were demonstrated in the *treatment* of rheumatic disease.

A 1988 analysis of Medicare data demonstrated a pattern of higher rates of total joint arthroplasty in the predominantly white Midwestern and Western states as compared with New York and various Southern states having much larger concentrations of African Americans [15]. This observation, perhaps the first to suggest racial disparities in health care related to the rheumatic diseases, ushered a new line of inquiry into the field of rheumatology. Subsequent study confirmed this observation and extended it to other ethnic groups including Hispanic and Asian populations in various regions of the country. For instance, Hispanics appear to be particularly underrepresented as recipients of hip replacement [16, 17]. Such differential rates of joint replacement surgery cannot be explained on the basis of racial differences in disease prevalence, access to medical care, or socioeconomic status. Potential explanations for these findings have

included different attitudes toward surgery as well as differential tolerances for pain and disability between Hispanic and non-Hispanics. It is likely that multiple factors are at play.

Studies involving another important rheumatic disease, systemic lupus erythematosus (SLE) also showed marked health disparities [18, 19]. For instance, survival rates among patients with SLE were reported to vary according to socioeconomic status and to differ among ethnic groups. Morbidity, as assessed by measures of disease activity, permanent organ damage, functional capacity, and health status, was also found to vary by socioeconomic status in some studies. Alarcon et al [18] demonstrated that disease progression, as measured by the SLE Damage Index, over a 5-year follow-up period was greater in Hispanic patients as compared with Caucasian and African American patients. Factors predicting such progression of disease included older age, greater lupus activity, Hispanic ethnicity, and household income below the poverty level. Furthermore, in patients with lupus nephritis, the natural history and response to therapy seems to vary among different racial and ethnic groups—specifically, patients of African American ancestry experience a worse prognosis than those of Caucasian descent. Indeed, so striking is this variance that the racial determinants may be nearly as potent in a prognostic sense as the intensity (i.e., low vs high-dose Cytoxan) of therapeutic interventions themselves [20].

In response to these as well as other considerations, leaders in the field of rheumatology have begun to comment on a growing disparity between the therapeutic advances in and the care received by patients with such diseases as rheumatoid arthritis [21, 22]. Indeed, some believe that the care received by patients with chronic disease in general is not keeping pace with new knowledge. Such concerns are rooted in the inefficiencies of our health care system, one better organized for short-term as opposed to long-term medical care. In the rheumatic diseases, various problems have been recognized, including outmoded models of health care delivery as well as a projected shortage of rheumatologists in the future. Already a medical specialty whose manpower is insufficient to meet the challenges of these, the most prevalent conditions afflicting our society, a shortage of professionals trained to deal with them can only further delay, if not prevent, patients from obtaining appropriate health care. Thus, the problem of health care access will only be exacerbated for those already disenfranchised based on their social, cultural, and economic characteristics. That these circumstances are arising at a time of unprecedented advances in the treatment of the rheumatic diseases is even more frustrating and indeed tragic.

Justice

These health disparities have important ethical implications and can be considered through the philosophical principles of *distributive justice*. A leading approach to justice in health care is that developed by Norman Daniels [23]. Developing his concepts on the seminal writings of John

Rawls [24], Daniels argues that a just society will strive to assure fair equity of *opportunity* for all its members. Central to Daniels' thesis is that the moral importance of the prevention and treatment of disease and disability, that is to say health care and its delivery, is derived from the way in which the preservation of normal functioning contributes to the protection of *opportunity*. Thus, by maintaining people as close to normal levels of function as possible, health care preserves the ability for individuals to fully participate and succeed in their lives. By analogy, just as educationally deprived children lack equal opportunity, Daniels argues that people deprived of adequate health care are also unjustly treated. Thus, it is through the maintenance of normal functioning that health care protects an individual's "fair share" of the customary range of plans for life (opportunities)—that is, the range of opportunity individuals would choose if they were not sick or disabled. This framework has important implications for the rheumatic diseases because these conditions decrease the individuals' access to societal goods.

Daniels argues for the special significance of health care by linking it to equality of opportunity. It is by impairing normal functioning that disease and its attendant disability restrict the range of available opportunity of those inflicted. Therefore, through its capacity to limit the impact of disease and disability, health care contributes to the protection of equal opportunity. This is especially true of the rheumatic diseases at the most basic level because they impair mobility. Mobility is essential to availing oneself of societal goods. Without mobility, individuals are limited in their ability to work and participate in valued activities, thus leading to a marginalized existence. It follows that a just society will strive to equalize such enabling abilities such as mobility.

Daniels also points out that multiple factors, both host-related as well as socially mediated influences, are additional important determinants of the susceptibility and perhaps the clinical expression of these diseases. Yet this concept of predisposition remains complex and, in addition to the role such predisposing factors as poverty and education may play, there is the growing evidence in a number of disease settings that race and gender may have effects across a broad range of inequalities.

Furthermore, Daniels introduces the problem of health care rationing and looks to the concept of *equity*. At present, the debate concerning rationing remains without consensus both on practical as well as philosophical (ethical) levels. Thus, in the absence of consensus on the necessary distributive principles, Daniels calls for the establishment of a fair process for making the necessary allocation decisions. Without such a process, resources that can generally be viewed as enabling with respect to the procurement of medical care (health insurance, geographic and physical access) may increasingly become the overriding influences. In so doing, they may reach dominance over the fundamentally more appropriate and morally correct influences of those related to need.

So what should be the response of the rheumatic disease professionals to address these concerns?

Promoting access

In considering our charge to improve access to competent rheumatologic care, it is helpful to start with the recent Consumer Bill of Rights and Responsibilities, which states that patients have the right to considerate, respectful care, free of discrimination [25, 26]. This mandate, coupled with a recognition of the unique vulnerabilities imposed by the rheumatic diseases, places a deep moral responsibility on all health care professionals charged with the care of patients with these conditions. Recognizing the sources of this vulnerability is therefore critical to the implementation of an effective corrective response. This is so because the inclusion of such vulnerable populations is required to account for them in the design of effective systems of health care delivery, in the choice of appropriate quality measures, and in the adaptation of payment mechanisms. In accord with recommendations of the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry [26], a number of general areas are worthy of consideration.

Broadly examined, we can consider how we might foster equitable rheumatologic care at four levels: clinical services, education, research, and financing. We will consider each in turn.

Clinical services

Traditional models of health care delivery often lack a number of important approaches to the delivery of medical care for those who suffer with chronic as opposed to acute medical conditions. Examples of such inadequacy would include a lack of systemic assessment, preventive care and education, inefficient coordination and integration of care, and insufficient psychosocial support. Considerations relevant to any potential corrective effort could include the use of multidisciplinary teams, would emphasize the importance of continuity of care, and would recognize the role of patient and family. Case management as well as outreach and home-based care would be other important components. Indeed, the rheumatic disease community might look to the Kennedy Bill or the "Quality of Care for Individuals with Cancer" legislation currently under consideration by the US Congress, the goal of which is to match the current excellence of cancer research with excellence in clinical care [27]. Acknowledging that advances in basic science do not always translate into better clinical care, the Kennedy Bill seeks, through an enhanced collaboration between academic medical centers and community-based organizations, to develop improved indicators of quality care, the bolstering of disease registries, and the funding of research directed at monitoring and evaluating outcomes as they pertain to cancer.

In response to these needs in clinical care the rheumatic disease community is beginning to explore new methodologies for health care delivery. Suggested approaches have included preappointment management, the use of physician extenders (nurse clinicians, physician assistants), the establishment of specialized clinics or specialty centers (so-called early arthritis clinics), and the development of

group programs (Arthritis Home Help Program [28], Bone-Up [29, 30]) as opposed to one-on-one physician visits. Regardless of the approach, the ultimate goal of these new paradigms of health care is outreach, both patient-directed and professional.

Emerging manpower considerations are also germane to this discussion. Underscored by observations that delays in diagnosis and therapy may be deleterious in the setting of rheumatic disease, the growing shortage of rheumatologists does not bode well for the provision of optimal health care to the rheumatic disease sufferer of the future. Some believe that in effect, there is no number of practicing rheumatologists that can dependably provide the required levels of care for this population of patients [23], an observation that supports the notion that different models of rheumatic disease care may have become necessary. Whereas such new approaches would likely involve the integration of internists, family physicians, and nonphysician extenders into the process of patient care, the complexity of the diseases and the associated therapy ensure both a preeminent role and continued need for well-trained rheumatologists and specialty centers. The American College of Rheumatology (ACR), medical schools, and academic rheumatology departments must assume a leadership role and responsibility in the development and definition of these evolving trends to bring equity to our society's need for comprehensive care for the rheumatologic diseases especially to underserved minority communities.

Education

The paucity of trained rheumatologists and specialty centers when contrasted to the prevalence of these diseases makes it abundantly clear that our field needs to vigorously pursue additional educational outreach. This should be viewed as both a potential force amplifier as well as a central ethical responsibility of the specialist rheumatologist. The responsibilities of the rheumatologist should not just be to "treat the many" but also to "educate others."

Educational outreach should be geared to improve the use of existing specialty resources. This would suggest that nonrheumatologists receive additional instruction in proper and timely rheumatologic referral and in the management of common musculoskeletal complaints that do not require the intervention of a specialist. The creation of curricula for the nonspecialist should be an important priority, one that perhaps should be developed through the already productive relationship with the ACR's sibling society, the Association of Rheumatology Health Professionals (ARHP). Medical schools and a variety of training programs (medicine, pediatrics, family medicine, physician assistants, nurse practitioners) should be considered as potential target audiences. Whereas millions of Americans now obtain a substantial part of their health information via the Internet, the disenfranchised, poor and uneducated are likely not to have availed themselves of this modern technology for financial, social, and practical reasons, thus putting them farther and farther behind.

Research

Research promoting innovation in the development of health care delivery models for patients with rheumatic disease is a vitally important challenge to the rheumatic disease community. Such efforts will need to take into account the health care needs of patients with chronic medical conditions as well as those who are disabled. Research exploring innovative new methodologies for the delivery of rheumatic disease care has been alluded to above and must be considered a priority. In the broader context of health care, it has been argued that vulnerable patient populations in general require special attention in the design of health care quality measures. The health-related problems singularly experienced by patients with rheumatic disease differ in important ways than those encountered by patients with other disease states. Whether general (health status) or targeted (disease specific) in their focus, the field of rheumatology has long recognized this issue both in the context of clinical care as well as in research and should be proud of its tradition of assessment. This important work, however, has been disproportionately targeted on specific diseases, mainly rheumatoid arthritis, and on the use of these tools in the performance of research as opposed to the evaluation of health care delivery.

Financing care

Current methods for the provision of health care insurance and payment neither reward high-quality care for patients with chronic medical conditions nor provide incentives for patients to seek early care for their rheumatic disease problems. To provide a stimulus for the systemic changes argued for above, payment methodologies, indeed medical insurance itself, should be designed to encourage models of health care delivery that have been shown to achieve superior medical outcome. Although there is still room for study in this regard, in rheumatic disease care, data exist suggesting that disparities and unfavorable outcomes may be linked with the type of medical insurance (traditional fee-for-service was superior to traditional indemnity). Thus, for patients suffering with a chronic, debilitating, rheumatic disease, perhaps payment for medical services should be constructed in such a way as to encourage multidisciplinary, broad-based, and coordinated treatment approaches that operate *across* the continuum of care rather than on a single individual at a single moment. Such comprehensive services across care settings have recently been proposed for palliative care [31].

A related concern with ethical implications for access to therapy is the issue of the cost of care. Although medications such as the new tumor necrosis factor inhibitors have been a spectacular therapeutic advance in the treatment of a number of rheumatic diseases, their current expense (approximately \$12,000 for a 1-year course of treatment) may be prohibitive for many who would benefit from such therapy. Indeed, in a recent report from Canada, the cost of medication was rated by practicing rheumatologists as the most important barrier to the provision of

adequate care [32]. This suggests a need for comprehensive formulary benefits as well as outcome studies examining whether early therapy with these medications will decrease the long-term morbidity associated with these conditions and possibly lower the costs associated with caring for these patients.

Conclusion

In this paper an overview is presented concerning what is known about inequality of health and health care in their relationship to the rheumatic diseases with particular attention to the determinants of access to medical care. As demonstrated in other disease states, characteristics such as race, gender, as well as other socioeconomic considerations were shown to be highly influential with respect to the medical care, specifically inequalities in care, received by these patients. Measured by the egalitarian concepts of Rawls and Daniels, inequality in health care is seen as an unjust loss of the opportunity to participate in a normative plan of life.

Disparities between the need for and access to medical services in the rheumatic diseases raise troubling questions about justice or fairness and present an ethical challenge for practitioners in rheumatology and the leadership of our specialty. The rheumatology community, in conjunction with its allied health professionals and their respective governing bodies, need to take the lead in redressing these issues and push to make our system more responsive to the needs of all those suffering from chronic rheumatic disease.

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