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Bioethical challenges to rheumatology in resource poor areas: a review

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Abstract

Objective: To outline the bioethical challenges specific to rheumatology in resource poor areas.

Data source: Published articles and selected personal communications on bioethical challenges and education in rheumatology.

Study design: A narrative commentary.

Data extraction: Online searches using PubMed and Google Scholar and personal experiences (Michele Meltzer, Amy Price).

Conclusion: Autonomy emphasizes respect for the individual and self-determination. We discuss how this can be dealt with because of lack of medical literacy. Moreover, conflict of interest should be revealed to the patient. Beneficence includes affirmative steps to improve public health and the role rheumatologists can play in advocating for increased public education and access to care for their patients. Nonmaleficence, encompasses the premise of doing no harm. Physicians need to be competent, but many parts of the world lack trained rheumatologists to teach the special skills required to diagnose and treat not only complex musculoskeletal disease but also chronic multifaceted pain conditions. Finally, we consider justice when fair allocation of scarce resources is difficult. Among other choices related to justice, physicians must decide how to allocate their time because of scarcity.

Introduction

A recognition of bioethical challenges faced by rheumatologists is important to develop a framework to manage or solve particular issues. In a 2013 survey, U.S. rheumatologists identified conflict of interest, the cost of modern treatment (to patients as well as to society), and a perceived deficit in ethics training among medical professionals, among other ethical challenges in rheumatology¹.

These challenges exist everywhere, to varying degrees depending on the economic, political and cultural situations within a given geographical region, but particularly in low- and Limited-Income Countries (LLICs).

This paper will discuss particular bioethical challenges within LLICs for rheumatologists and their patients. The four basic and well-known principles of bioethics will be used to guide the discussion: autonomy, beneficence, nonmaleficence, and justice². We note that one complication is the international lack of research and methodology manuscripts that are culturally and resource specific to practitioners in low-income settings. Clinicians are ill-equipped and struggle to give appropriate care when access to medicines, devices, supportive care, and consultants are limited. It can be challenging for each rheumatologist to decide what part he or she shares in the burden and/or responsibility for health “equity” so that everyone has fair opportunity for health within the medical system³.

Case study

We begin by exploring the following case example. A caring father brings his six-year-old son to a rheumatology clinic in Nairobi. The child has severe destructive juvenile idiopathic arthritis and cannot walk or even feed himself because of the deformities. Two years earlier, the father had taken the boy to a rheumatology clinic, and he was started on methotrexate and prednisone. But the father did not return because it was an eight-hour bus ride to attend clinic and he could not afford the bus ride nor the time missed from work. The father did not understand how sick his son was and the consequences of not taking medication. Now, there is permanent damage to the boy’s joints and the boy will never be able to live independently. The medical team decides to admit the boy for the

management of his rheumatoid arthritis, however due to resource limitations they are only able to administer corticosteroids. The medical team felt helpless and just wanted to do something. The lack of resources and training caused them to overlook the fact that hospitalization was unwarranted as the patient could receive corticosteroids as an outpatient. They were despondent that once again the medical system failed a vulnerable child. One could argue that the hospital admission is just more money wasted and the toxicity from the prednisone will just compound the suffering. The treating physicians are stuck at what to do next. There are no rehab facilities for children and orthopaedic surgery would be too expensive and very complicated.

Foundational principle of bioethics: Autonomy

As one of the foundational principles of bioethics, autonomy emphasizes respect for the individual and self-determination. This concept involves having the authority to make decisions for oneself, having sufficient information in order to make an informed decision, and having one's own choices be respected by others. But this concept is complicated by the fact that many parts of the world embrace a value system that places the family, the community, or the society as a whole above the individual person^{4,5}. The individual patient should have the right to decide if he or she wants to delegate decision-making authority over personal care to a surrogate, such as a family member. The challenge facing bioethics in a resource-poor setting is not to mislead people with unrealistic promises of autonomy that very few communities can achieve, but to articulate moral principles and societal values that promote equitable access to care and broaden the goals of medicine and public health⁶.

The opening case highlights a few of the bioethical challenges to autonomy. The father delayed follow-up treatment, either due to ignorance about the particular illness or to the high cost of care. As a result, the child presented to the clinic too late to benefit significantly from treatment. But, as we will discuss, the medical staff may not have had the resources to fully inform the father about his son's disease. Another issue is that there are alternative practitioners of medicine in many LLICs. It is not uncommon for people with less education to seek care from these alternative practitioners, who often encourage the patient to discontinue conventional therapy⁷. The combination of an absence of a referral system, a lack of insurance, and a limited understanding of the disease created delay in seeking appropriate care⁸.

In order to effectively participate in the decision-making process, the patient must be informed about his or her disease process in vernacular that is readily understandable. The need to improve medical literacy is a global problem. Many rheumatic diseases are complex,

and every effort should be made to ensure the patient understands the medical condition and treatment options⁹. Even when the patient recognizes the need to seek treatment, this acknowledgement may be insufficient in areas of severe poverty and pose further ethical challenges that are less common in more developed countries. For many patients, spending time in the hospital means a loss of earnings and puts the family's economic well-being in jeopardy.

Informed consent and literacy: Low levels of education, literacy, and health literacy, which are associated with poor health¹⁰, can make even informed consent a challenge. However, prior to any procedure or research, the patient should give informed consent. When seeking the consent of a financially stressed patient to participate in a research study in exchange for remuneration, care must be taken so that the arrangement is not coercive. Each research candidate should receive adequate disclosure of potential risks and unknowns involved with the study, as well as information about other treatment alternatives that are more established. Documentation of responsibility for adverse events should be made available. Moreover, the definition of adverse event, and the length of time from the start of treatment to adverse event, needs to be part of the informed consent process.

Informed consent also requires that the physician discloses any conflict of interest. Many countries recognize the influence on physicians from perks and financial payments provided by pharmaceutical companies, and have implemented restrictions on such activities as well as public reporting requirements¹¹. These interactions can bias a prescriber's choice of medication in favour of more expensive drugs with no clinical evidence showing that they are more effective than less costly drugs^{12,13}. In the United States, patients can now access a public website to view legally required disclosures of income and other financial benefits received by healthcare professionals from pharmaceutical and medical device companies¹⁴. All over the world pharmaceutical companies have a history of providing stipends to attend conferences, deliver training and for Continuing Medical Education (CME). Research has found this influences prescribing habits regardless of the efficacy of the intervention¹⁵.

External considerations in autonomy: In low income countries clinicians face increasing pressure in the struggle to provide for their families and their patients. For example, when the clinician wants to send their own children to university or pay for a relative's ongoing medical care those stipends carefully saved can make the difference between meeting the need or seeing the family need left unmet. There is a real concern that over time this may unconsciously influence how the doctor makes a choice about what to provide in terms of prescriptive

interventions. The information about potential conflict of interest and how this could occur might be disseminated within the community and should be shared with the patient and the clinician. By the same token, medical students must also be alerted to the potential conflict posed by receiving financial benefits and gifts from pharmaceutical companies.

Privacy and confidentiality: Finally, medical confidentiality is one of the cornerstones of respect for patient autonomy. Patients need to know that what they discuss with the healthcare professional is private. If not, they will be reluctant to reveal sexual history, diseases that could affect employment, and mental health. When author, Michele Meltzer (MM) served as a visiting consultant in Africa and India in 2011 to 2015, privacy was almost non-existent. Often more than one patient at a time was in the exam room, and in the hospital wards, curtains were either not available or not drawn when the patients were interacting with medical staff, and of course curtains do not block sound. Further complicating the issue of privacy, many patients MM saw in both Kenya and India carried their medical records with them. As LLICs develop electronic medical records, policies on medical record access and security will evolve¹⁶.

Foundational principle of bioethics: Beneficence

The principle of beneficence includes public health and taking affirmative steps to enhance it¹⁷. In many areas of the world, treatment for rheumatic diseases is not available, and accommodations are insufficient for people with disabilities¹⁸. For instance, in most of sub-Saharan Africa, musculoskeletal health has been almost completely neglected principally due to fierce competition for scarce resources¹⁹. It is common for public health to take priority and this means that resources are directed towards infectious disease and maternal care. A disease that does not spread is given lower priority even though an infection may last only a few days while a chronic or immune disease left untreated can shorten the lifespan and cause disability for a lifetime. Rheumatologists and their patients need to educate policymakers and non-profit organizations about the incredible burden, including years lost to disability, and inability to contribute in the workplace that rheumatic diseases create for individual patients and for society²⁰⁻²³. Epidemiology studies on the prevalence and impact of rheumatic diseases would be of great value to raise awareness, prepare families and to advocate for care.

Peer to peer resources: Consider systemic lupus, an autoimmune disease with variable manifestations. Rheumatologists are in a position to improve patient education about the disease. When one of our authors Michele Meltzer (MM) attended two meetings of the

Lupus Support Group in Nairobi in 2012 and 2013, she met people who were eager to learn more about their disease and enjoyed the camaraderie from meeting others with similar diseases. Another author Amy Price (AP) found the same in her trips to these nations and was impressed with the willingness of the sick to attend to and comfort each other. It has been observed that even the elderly are willing to learn electronic communications skills so they could form communities of learning around the disease²⁴. Many felt socially isolated by having a disease no one seemed to have ever heard about. They knew little about their disease and lacked personal resources to find more information²⁵. These patients would benefit from knowing that medications are available that may help. Support groups are in a position to advocate for the availability of these drugs and also for the rights of those disabled by the disease and their families. Although more work needs to be done, both authors found such support groups can reduce psychosocial factors and improve disease self-efficacy and quality of life, especially in areas where the physicians have a large patient load²⁶.

Foundational principle of bioethics: Nonmaleficence

Access to knowledge: The principle of nonmaleficence encompasses the premise of doing no harm. Physicians must be competent, having not only a wealth of technical knowledge but also an understanding of how to manage the complexities of chronic disease within their own communities. Achieving this competence in rheumatology is challenging because there is a worldwide shortage of rheumatologists. For example, Canada suffers from a shortage of rheumatologists and is actively exploring ways to make rheumatology more attractive to students²⁷. The shortage of rheumatologists is especially severe in LLICs²⁸. As a result, the many medical schools in Africa will have an insufficient number of instructors in rheumatology, which in turn will likely result in fewer graduates entering the rheumatology field and a general deficiency in the basic understanding of rheumatic diseases²⁹. In 2005, there were 4,946 adult rheumatologists and 218 paediatric rheumatologists in the United States³⁰. Meanwhile in sub-Saharan Africa (excluding South Africa), less than twenty rheumatologists are available to serve about 800 million people^{18,31}. Physicians do not work in a vacuum. Trained nurses, physiotherapists, occupational therapists, to name a few, are part of the professional team that lack the specialist training for the treatment of musculoskeletal disorders. There are too few specialists to treat patients and train staff compounded by the added challenge of lower healthcare professional training standards. These diseases require specialized care and an inaccurate diagnosis can do great harm. For example, a young man with back pain due to ankylosing spondylitis might be diagnosed and treated for degenerative disc disease. In the meantime, he

develops irreversible changes in his spine. Or a young woman comes in with joint pain. No one has the skill to question her further and find that she has symptoms of systemic lupus and in fact her most serious problem is her kidneys are failing.

Access to care: But knowledge is not the only important factor in nonmaleficence. Students also require tools to analyse and understand major ethical issues, such as drug and medical device counterfeiting and the quest for profit³². Scarcity of resources also requires physicians to make difficult choices about intensive care, access to surgery, and use of medications, as documented in a survey of Ethiopian physicians³³. Problems of resource scarcity in many LLICs are compounded by political instability, corruption, and severe income inequality. Even something as basic as reliable electrical supply restricts availability of medications which require refrigeration.

The role of advocacy: In the United States, the American College of Rheumatology provides practice guidelines, educational material for both physicians and patients, and advocacy in the government^{34,35}. In all nations the influence of pharmaceutical companies can influence selection of drugs by doctors. The costs may be higher and efficacy lower for advertised drugs. When specialist education is absent and medical journals are unavailable due to lack of access, the medical staff may look to a pharmaceutical representative for advice on how to treat patients. The inducement by gifts, trips to conferences and personal incentives is currently not under tight regulation in LLIC nations and this has the potential to influence the choice of drugs prescribed by the treating professional. More work is needed to elucidate the magnitude of this problem and then make physicians and healthcare professionals in LLICs aware. They can then create similar professional organizations in order to develop their own practice guidelines, educational materials, and advocacy committees. They are in a unique position to understand the difficult local challenges to patient care and could work together when confronted by difficult situations. Not only can these groups work with guideline developers to include information unique to their culture, they can negotiate with local officials to improve access to treatment and diagnostic studies. But most importantly, they can serve as a resource for individual physicians/health care workers to work together to make decisions about how best to deliver scarce care and provide emotional support to one another.

The biologics and newer medications now available for many conditions in rheumatology are extremely expensive and this means only those with sufficient financial means will benefit. Physicians should carefully consider alternative options to determine the most clinically effective and cost effective treatment. For example, triple therapy for treatment of rheumatoid arthritis

(methotrexate, sulfasalazine, and hydroxychloroquine) treats rheumatoid arthritis effectively, and for a fraction of the cost of a biologic and may make the use of a biologic unnecessary³⁶. Furthermore, prior to ordering expensive tests and medications, physicians should consider the financial impact to the patient and his or her family. Although defacto rationing is part of daily life in LLICs, ethics committees or local physicians can create criteria for the fair use of various medications and tests. A good resource for physicians and patients is "Choosing Wisely"³⁷. Developed under the auspices of the American Board of Internal Medicine and Consumer Reports, Choosing Wisely lists diagnostic tests that are over utilized based on medical necessity, according to professional organizations that were asked to name the five most over utilized tests in their specialty of medicine. This excellent teaching tool increases awareness of these tests and decreases wasteful medical treatment and spending. The combination of community awareness, education, and fair use of medications may contribute to early and proper management and this could lead to better outcomes and increased quality of life for patients and the family members who care for them.

Managing corruption: Corruption is another problem that can reduce access to care. In Africa corruption was found to be a major barrier to patient access for cancer care. The health care systems, to varying degrees, were subject to bribery, extortion, and nepotism³⁸. Those with rheumatic illness are also vulnerable. Anti-corruption strategies, such as transparency and accountability, agreed codes of conduct, whistle-blower protection, and enhanced benefits for workers, could stave off corruption trends. Specialized Drug Shops (SDSs) provide distribution for most medications in sub-Saharan Africa. But medication distribution is another area that is poorly regulated. For example, only 12% of the SDSs in Kenya have refrigeration³⁹.

Foundational principle of bioethics: Justice

Allocation of resources is a major issue for all healthcare professionals, especially those with limited resources. Albert Jonson, medical ethicist and historian, has said that even artfully applied science, effective cures, and cost-effective care are morally deficient if such science reaches only some, if cures are unaccompanied by effective efforts at prevention, and if cost-effectiveness means limiting care to the elderly, the poor, chronically ill or the dying patient⁴⁰. John Stuart Mills, philosopher, when struggling with how to decide who is worthy of scarce resources, developed the theory of utilitarianism that advocated allocation so that the greatest number benefitted⁴¹.

On an individual level, the rheumatologist is torn because of limited time to see patients. Even in the clinic, a decision must be made whether to see more patients in

a cursory fashion or spend more time with fewer patients. Physicians need to care for family and extended family expenses as well as consider the schooling of their own offspring. It can be a difficult choice to work in the city where there is the support of peers and financial stability or in rural areas where there is little financial advantage or room for advancement. They struggle to balance the advantages of the more lucrative private system where conditions are better for those who can afford to pay or to meet the need of the population within the public system. Decisions for diagnoses and treatment are equally difficult. With limited funds how does one decide if a particular treatment or diagnostic test is worth the financial burden it will place on the patient and their family? And finally a nation's health professionals will face the issues of how tribal identity, sex, and race will influence fair and equal access to health care.

Conclusions

Common challenges to the practice of rheumatology-conflict of interest, cost of therapy, deficits in bioethics training-are compounded in LLICs by limited income, political instability, war and corruption. The determinants of health are much more complex than in Western countries with competition between ethnic groups and volatile unstable economies⁴².

As the number of rheumatologists in LLICs increases, education in bioethics is essential to understand the theories needed to create policies to improve the complex medical systems. The opening case illustrates various aspects of medical ethics discussed in this paper. The father did not understand the seriousness of his son's disease. Medical access complicated the problem, and the treating physicians did not have the tools to help his son once he did reappear in the medical system. Even on a personal level, individual practitioners need guidance to sustain daily practice without burnout. Organizing gives rheumatologists and those involved in treating arthritis the collective expertise to advocate for their patients and increases public awareness about the diseases they treat. Educational resources on rheumatic diseases can be made available for allied health professionals, politicians, and the public. As a group, rheumatologists can lobby for necessary medication that is distributed in a safe manner. They can also explain that they have a special expertise that requires extensive education. They need to have a referral system in place so that patients with rheumatic conditions, such as rheumatoid arthritis or systemic lupus, can be seen in a timely fashion. In this way, they can promote a moral practice of medicine where principles of autonomy, beneficence, nonmaleficence, and justice are practiced. We end with a suggestion that rheumatologists organize in order to collectively devise ways to cope with the conditions unique to their own communities.

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Competing interests

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