

Sugar Blues: The Social (Silent) Side of Diabetes

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I met Norman soon after he was diagnosed with type 1 diabetes. This formerly energetic and slender 50-year-old bachelor lived with his aged mother in the Santa Cruz Mountains and rarely visited doctors—only when he felt sick.

Because Norman was self-employed and his finances were modest, he had decided that his best bet was to forego health insurance and to pay for medical services only when he needed them. Yet when diabetes intruded on his life, the financial burden surpassed his worst expectations. Among other things, he discovered that buying health insurance would never again be an easy or inexpensive option.

Norman's diabetes was discovered when ketoacidosis was diagnosed in the emergency room of the local hospital, where he had come because of sustained weight loss and an unquenchable thirst, but primarily because of a persistent cough that was seriously impairing his ability to work. The shock of diagnosis was followed by a week in the hospital, where his condition was stabilized and he was started on a split-mixed dose of NPH and lispro insulin (Humalog), fed a "diabetic diet," and provided with educational materials that were to be his main source of information about diabetes, at least for the first few months.

From these materials, Norman gleaned a clue as to why, while in the hospital, he often felt shaky and craved sugar. His insulin shots at times were not well matched to his meal schedule, probably, as Norman guessed, because of a shortage of hospital staff. Shortly before

discharge, a sympathetic nurse encouraged Norman to do his own shots and finger-pricks for glucose monitoring. These competencies proved invaluable when, at discharge, he was instructed to check his blood glucose four times a day, write the results in a logbook, follow a split-mixed insulin regimen, and follow a printed diet sheet until a follow-up appointment with the endocrinologist 3 months later.

Norman was warned that, in the event of three consecutive "bad" readings (blood glucose >300 or <80 mg/dl), he should contact the nurse, who would contact the endocrinologist, who would then give instructions on insulin adjustments.

Last, but certainly not least, Norman was given a hospital bill roughly equivalent to his annual income. This bill left Norman acutely aware that his medical bills would not become any smaller. At least for a while, securing the services of a diabetes educator (highly recommended in the educational materials) would not be his first priority.

My aim here is not to provide a technical account and analysis of Norman's initial or follow-up medical care or his hospital bill. Fixed-dose insulin regimens, "diabetic diets," and criteria regulating the delivery of medical services in hospital settings have all been exhaustively examined.^{1,2} State-of-the-art diabetes care is periodically discussed in continuing medical education activities and outlined in the annual Clinical Practice Recommendations of the American Diabetes Association (ADA), available at no cost at the ADA website. Suffice it to say that Norman's case was not exceptional and that many

diabetic patients, whether recently diagnosed or not, have little if any real choice about whether to receive good diabetes care or lifesaving diabetes instruction nor the means to follow whatever instructions they are lucky enough to receive. Furthermore, Norman's story does not illustrate the state of affairs in some lost, underdeveloped community, but rather in a community just a few miles away from world-renowned medical research and treatment centers.

Although not easy to achieve, good diabetes care is not rocket science. The notion that the best care is that which attempts to mimic normal pancreatic function within the limits of available technologies makes intuitive sense to anybody trained in human physiology and was scientifically demonstrated by the Diabetes Control and Complications Trial and the United Kingdom Prospective Diabetes Study.^{3,4}

Cutting-edge research notwithstanding, efforts to apply this knowledge to clinical practice have often left much to be desired.⁵ Even when the best diabetes care and education practices are available, it is difficult, if not impossible, for many people such as Norman to take advantage of them, given their out-of-pocket costs. It may be true, as is often claimed, that diabetes research is underfunded relative to research into other diseases,⁶ yet it is also true that the United States, nonetheless still at the forefront of this research, allows 44 million of its 300 million population to go not just without *quality* health care (diabetes or otherwise), but without *any* health care at all.⁷⁻¹⁰

Diabetes and Policy

I recently learned that the federal End-Stage Renal Disease Act came about as a result of political pressure stemming from the mass-media revelation of the “God Committee” at the Swedish Hospital in Seattle, where decisions about who would benefit from hemodialysis, a scarce and expensive treatment, were based on standards of morality allegedly defined by members of this committee. In 1972, this pressure compelled Congress to legislate a “right to medical care” of sorts (limited to hemodialysis) for anybody who qualified strictly on the basis of medical necessity.¹¹

Now, there is good evidence that one of the leading causes of kidney failure is diabetes-related kidney disease. This disease is a function of the duration of diabetes, but even more so of the quality of diabetes control achieved, which is in turn largely a function of access to quality care.³ Although providing quality diabetes care is time-consuming and expensive, dialysis is neither fast nor cheap itself. In fact, diabetes complications including nephropathy account for a big slice of the cost-of-diabetes cake, aside from the non-trivial differences between the quality of life enjoyed by complications-free diabetic patients and that of those on dialysis.

Let us reflect on the rather obvious question of why we have a policy granting a universal right to hemodialysis when a person’s health is in hopeless decline when we do not provide for a right to adequate medical care when most, if not all, of life’s possibilities are still to be enjoyed. What are the rationale and values underlying such health policies in the United States?

We read that diabetes affects people of any age, gender, or nationality, “including all races and ethnic groups, the rich and the poor;”¹² yet diabetes does not behave like an “equal opportunity disease.” Both the disease and its complications disproportionately affect ethnic and socially disadvantaged populations.^{6,13–16} It is strictly type 2 diabetes

that is considered an epidemic and for which socioeconomic factors such as access to medical services have been found to correlate strongly with acquiring the disease.¹⁷ But when the disease is already in place, complications can occur in both type 1 and type 2, and in both types, access to adequate care is crucial to prevent these complications. Securing access to quality diabetes care and supplies would not resolve the problem of diabetes, but it would certainly take care of many of its undesirable effects.

Risk in Diabetes: An Alternative (Sociological) Analysis

As part of my work in the sociology of risk in diabetes, I recently conducted a discourse analysis (an analytic process to uncover assumptions underlying knowledge claims), the objective of which was to explore how the diabetes literature (lay and expert) accounts for risk.

I attempted to articulate the public understanding of what constitutes the primary locus of risk of developing diabetes or its complications—the individual affected, factors beyond the individual, or a mix of both.¹⁸ I found that, although there is evidence of both individual and social factors accounting for risk of diabetes or its complications, high risk is overall understood as the patient’s “problem,” whether biological or psychological (e.g., particular genes, unhealthy lifestyles, poor compliance, psychological denial, or lack of family support). Social-structural factors of risk (e.g., lack of access to adequate diabetes care, poor medical practices, or broader social disadvantages such as low socioeconomic status) are underestimated as risk factors in their own right. High risk is attributed, in the final analysis, to a person’s heredity, behaviors, psychological makeup, or cultural affiliation.

One example of what I called an individualistic view of risk is the use of the qualifier “environmental” (as in “environmental risk factors”) in both the medical and lay diabetes literature. The

categorization of risk factors either as “individual” (the genes and heredity of the patient) or “environmental” (patterns of eating and physical activity) refers ultimately to aspects, either biological or behavioral, of individuals.¹⁹ Another example is the Behavioral Risk Factor Surveillance System, a document that emphasizes the strong, negative correlation between socioeconomic status and access to health services (as predictors) on one hand and risk of diabetes on the other hand, yet interestingly purports to track “behavioral” risk factors.²⁰

I am aware that my sampling of the literature is neither representative nor random and that its statistical significance is unproven. (The universe is difficult to define, and I did not conduct any quantitative analysis of my data.) Granted, there may be more to the problem of diabetes than meets the sociological eye. Yet I would like to use my analysis on risk to discuss certain overlooked aspects of diabetes care and to suggest that the individualistic view framing most debates about diabetes makes three major themes in the literature—cost containment, evidence-based practice, and patient empowerment—problematic at best, and a catch-22 at worst.

In the area of cost-containment, there is much confusion about on what we are saving and who benefits from the savings. Two topics are frequently omitted in discussing the problem of rising costs in diabetes care, namely, the social organization of roles in the current health care system and the fact that health care is considered essentially a market commodity rather than a social good. This omission, in my view, lies at the heart of much of the confusion.

With respect to the social organization of roles in health care, despite the current trend to refer to patients as “clients,” today it is primarily the health insurance industry that is the “client” of the medical profession, because it is the primary payer for health care services. Thus, this industry, rather than the recipients of the care, defines cost-saving criteria—and even those of *medical neces-*

sity and quality—in its own terms, regardless of whether these terms conflict with medical standards or patients' medical needs.²¹ “Cost-saving” strategies may be successful with respect to the pockets of this industry while having a negative impact on the pockets—not to mention health—of ordinary people.²²

The implicit understanding of health care as essentially a market good obscures even further the problem of costs in diabetes (and elsewhere), because when care is delayed or foregone (which poses a challenge to cost-control), the problem is usually framed as people merely choosing any old commodity over a visit to the doctor. Commodities, of course, are seen as interchangeable, and their acquisition is viewed as a matter of choice. Yet this framing of the problem begs the question of whether there exists any actual choice in obtaining good diabetes care. In short, discussing costs in diabetes care seems problematic when the social organization of diabetes care and its treatment as a commodity are ignored.

In the area of evidence-based practice, health care organizations often require providers to produce scientific evidence supporting their practices, with the alleged intention of limiting unnecessary or insufficiently proven medical interventions and thus protecting patients' well-being and interests while also containing costs. Yet, often, insistence on evidence operates to the detriment of “soft,” difficult to prove, but critically important interventions, such as simply taking time to listen to patients. Given the complexity of the current social organization of health care delivery discussed above, I suspect that often, insistence on evidence merely conceals interests that have little to do with a concern for patients' welfare or with setting limits to alleged medical greed or incompetence. Worse, maybe this insistence is slowly undermining the wholesome ideals of many who chose medicine as a vocation.²³ Meaningful debates about evidence-based practice require a sociological awareness of the economic inter-

ests underlying the delivery of medical care.

Yet another area that can benefit from sociological insight is that of patient empowerment, which includes such activities as raising awareness of the seriousness of diabetes, encouraging patients to choose the best lifestyle and diabetes care goals for themselves, demanding adequate care, and fighting for a cure, however formidable the latter goal may be, particularly in the case of type 2 diabetes for which complex pathophysiology is intimately intertwined with the social, political, economic, and cultural milieus.

Attempts, however well intentioned, to empower patients to choose a style of diabetes care that fits their needs or to fight for their rights and freedoms are problematic if choices and freedom are seriously limited by social and structural conditions and if this limitation is ignored.²⁴ Take the epidemic of childhood obesity and type 2 diabetes as an example. For many families in populations at high risk, will and choice are insufficient to keep their children free from disease. A television set that teaches the kids the delights of junk food may be the only baby-sitting “choice” for working or poor parents. Neither emphasis on parental responsibilities nor presidential calls to prioritize physical activity can make healthy food choices accessible, nor can they undo the damage inflicted by an insatiable food industry, including the “health food” industry, which often sends misleading messages about the benefits or evils of particular nutrients and leads the public to misinformed, unhealthy consumption of reduced-fat or no-sugar products. A sociological analysis of the circumstances surrounding choice is called for to make any sense of the notion of individual empowerment.

The Sociological Imagination: A Path to Hope and Change

If there is any truth in the claim that much of the problem of diabetes is embedded in societal structures of which

the health care system is merely one aspect, what can the medical community and particularly individual health care practitioners do to diminish at least some of the suffering, disability, and death caused by diabetes? I wish I had a simple answer, but I must confess I do not. My commentary is intended merely as an invitation to reflection aimed at individual health care providers, but not individualistic in spirit, since I hope that the aggregate of individual changes will eventually reach a critical mass that will bring about change in the collective medical consciousness and perhaps even touch policymakers. Mine is an invitation to actively exercise the *sociological imagination* in everyday medical practice.

Often in doctor-patient encounters, we forget that, to paraphrase C.W. Mills, the life of an individual is intertwined with the history of the society he or she belongs to, to the point that neither can be understood without a permanent, active awareness of each other.²⁵ Maybe because of our clinical training to focus on conditions, we tend to see our patients' troubles just as their personal troubles, rather than, perhaps, the other side of the coin of public problems. People, Mills argues, “do not usually define the troubles they endure in terms of historical change and institutional contradictions.”²⁵ The capacity to make these connections can only result from a purposeful exercise of the sociological imagination, which involves being engaged in the here and now of medical practice, while simultaneously keeping open a sociological eye.

Interestingly, this bifocal vision in medical practice is not new. Nineteenth-century German physician Rudolf Virchow, remembered more for his work in cellular pathophysiology than for his writings in social medicine, was an active practitioner of this vision.^{26,27} In investigating the origins of specific illnesses, Virchow attributed a major role to social, political, and historical contexts. His best-remembered book *Cellular Pathology* notwithstanding, it was

quite contrary to his vision to explain disease in terms of cellular pathophysiology. In contrast to contemporary emphases on personal factors in the etiology of disease, Virchow's writings emphasized social aspects of disease and underscored researchers' roles in advocating social reform.

This vision needs to be recovered not just to effectively address the diabetes epidemic in America, but also to re-enchant the practice of diabetes care. I am not proposing that we abandon genes, lifestyle, costs, or the like in researching or discussing diabetes. I am only suggesting the dangers of pushing social-structural and ethical factors to oblivion. Much pain has been relieved by acknowledging the deep social roots of infectious or toxic-waste-related diseases.^{28,29} The same needs to be done with diabetes, a disease for which the chase for "the genetic connection"—even the specific ethnic gene³⁰—or the ultimate behavioral link seems to have become a moral obsession.

I am also suggesting that the social nature of diabetes is intertwined with social values underlying public decisions about how to distribute scarce and valuable resources, values that need to provide the general framework for, and be explicitly placed at the forefront of, diabetes-related discussions. Values—as studied in normative ethics—express what we should stand for, what lives we ought to live. Normative ethics is not empirical science, and no "outcomes" determine in any empirical sense which policies or social practices we ought to choose; they only suggest what to do depending on what values we have chosen as practitioners and as a community. In devising appropriate measures to address the risk, prevention, and treatment of diabetes, a due consideration of this disease's social, political, and ethical dimensions may help the medical community rethink ways of addressing these problems in a critical, creative, and ethically conscientious way and give a

broader social context to our discussions and practices. More generally, it may also help redirect the application of the wealth of medical knowledge already available.

In the light of these considerations about ethics, advocates for the diabetes community should encourage groups who shape discourses and debates about diabetes in the public sphere to rethink individual and social responsibilities vis-à-vis the best starting points for better and "healthier" medical practices and health policies.

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