Epic Fail: Prenatal Care for Women with Mobility Impairment

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PRENATAL CARE CAN ease the discomfort and anxiety of pregnancy, address risk factors for preterm birth or poor pregnancy outcomes, and reduce the likelihood that complications will affect the health of the mother and baby (e.g., preeclampsia, breech presentation).¹ Accordingly, women receiving prenatal care perceive it as their best chance of reducing fetal morbidity and mortality.^{2,3} As with all healthcare delivery, there is a social contract: the patient engages in behavior that will optimize pregnancy outcomes (abstaining from alcohol, eating healthily, and remaining active) and the clinician treats the patient with dignity, attempts to respect her wishes (e.g., acceptance of screening tests or construction of birth plans), includes her in decision-making, and provides high-quality care. This contract extends to all patients, regardless of their demographics, concurrent or ongoing medical conditions, or disabilities.

The 1990 Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act state that providing care for patients with disabilities is both ethical and required by US federal law.⁴ Prior research has demonstrated that patients with disabilities frequently receive lower quality care than patients without disabilities,⁵⁻⁹ but no studies have focused specifically on prenatal care. One study did report that almost half of gynecologists (44%), some of whom likely provide prenatal care, would deny appointments to patients with a mobility impairment.⁷

In this issue of *Journal of Women's Health*, Iezzoni *et al.* report the results of a qualitative study examining the prenatal experiences of 22 mothers-to-be with mobility disabilities.¹⁰ Their results are disturbing and demand intervention. Many women with mobility disabilities reported that their obstetricians did not own height-adjustable tables or lifts. As a result, women were transferred from a wheelchair to the examination table in a manner that was potentially unsafe for both the patient and the staff. One woman reported being dropped three times during her pregnancy, putting both her and her pregnancy at risk. Some reported that by the end of their pregnancy, the physician stopped performing examinations altogether. None of the interviewed women was regularly weighed during their pregnancy; four reported never being weighed at all. Many women described humili-

ating experiences as they attempted to receive routine prenatal care (one woman was told to go to the post office to get weighed) and many reported emotional distress. While the women represent a selected population recruited using social media websites, prior research supports these experiences as typical.⁵⁻⁹

From a civil rights and legal standpoint, it is clear that these women's clinicians were violating federal law. There are important concerns from a medical standpoint as well. While the benefits of prenatal care for healthy women with uncomplicated pregnancy are still a subject of debate, prenatal care offers clear benefits for both mother and fetus when medical complexity or other risk factors are present,¹¹ as might be seen in women who use wheelchairs because of illness or injury. For example, weight loss or failure to gain weight during a pregnancy can be a measure of the severity of hyperemesis gravidarum or alert the clinician that the fetus is at increased risk for intrauterine growth restriction and low birth weight. Rapid weight gain near the end of a pregnancy can signal that the patient is developing preeclampsia and needs monitoring or early delivery. Because none of the women in the study was regularly weighed, their clinicians missed the opportunity to optimally identify these conditions and potentially prevent poor outcomes. The clinicians also failed to comply with guidelines published by the American College of Obstetricians and Gynecologists, which recommend weighing patients at every prenatal visit.¹²

Perhaps most importantly, research indicates that when women report feeling respected during prenatal care, they report higher satisfaction and are more likely to actively participate in their care.¹³ Many of the women in this study felt disrespected by their physicians and the healthcare system. This alienation could leave them less likely to report changes in their health or new medical concerns, risking poorer maternal-fetal health and pregnancy outcomes.

How can this situation be remedied? First, clinicians must receive training as to how to best provide hands on care for these mothers. Second, they need to be educated about the best strategies for serving patients with mobility disabilities. This includes facilitating physical access by creating an environment free of physical impairments to care (e.g., ramps, parking,

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doorways, and bathrooms)¹⁴ and providing accessible equipment (adjustable height tables, lifts, and scales).^{14,15} While height adjustable tables may initially seem expensive, they can potentially appeal to all patients, not just those with disabilities. Patients come to medical offices because, in general, they are old, sick, or, in this case, pregnant. Traditional examination tables are cumbersome and might not serve any of these patients well, while a height adjustable table caters to the needs and experience of diverse patients.

Of equal importance to physical access is the need to examine policies and procedures that result in barriers to access. One key policy is the systematic collection of patients' disability status. Instead of relying on the patient to specify her needs before or at the time of the appointment, clinicians should systematically collect this information through intake forms that inquire about accommodations and include standardized validated questions that identify the majority of patients with disabilities within a practice.¹⁶ These data, which are periodically updated to monitor change in a patient's needs over time, should be integrated into the medical record and scheduling systems. While collection of this information is not sufficient on its own, it can be used to identify patients who could benefit from accommodations before their arrival. This allows for universal accessibility of scheduling, staffing, and administrative resources; a patient with mobility impairment who presents for an appointment is automatically assigned a room with a height adjustable table, and staff can be available to assist with transfer. This approach is similar to placing flags into the electronic medical record to indicate patient allergies.

Existing incentives designed to encourage practices to improve access are available but may not be well known. Tax credits are available for private practices to offset some of the expense of accessible equipment. These credits allow up to 50% of costs of equipment that is ADA compliant, up to \$5000/year. In addition, many larger health systems could potentially reduce the chance of incurring financial penalties associated with poor patient experience of care by improving access and thus patient experience. Having accessible facilities and equipment also has the potential to reduce staff injuries and could improve access to preventive care, thereby reducing costs for some patients.

While education of the financial and legal implications of accessibility is important, it is clearly not sufficient. Many articles in the medical and the lay press have highlighted potential solutions, including a "how-to" guide that appeared in the *New England Journal of Medicine*.¹⁴ However, there is little evidence that physicians are making efforts to purchase accessible equipment or alter their policies and procedures to better serve patients with disabilities.

One potential reason that individual physicians have been slow to act may be due to the fact that most enforcement of the ADA and Rehabilitation Act has occurred through case-by-case litigation.¹⁷ This places the onus on patients to press for change, and patients may hesitate to bring complaints or lawsuits against their physician or midwife, especially if there is no available alternative clinician.¹⁸ Potential alternative approaches have been suggested. First, access for patients with disabilities should be a requirement for accreditation from organizations such as the Joint Commission on Accreditation of Healthcare Organizations or State Departments of Health. Second, there should be improved oversight of contracts with Medicare and Medicaid (which generally include a clause

stating that access for patients with disabilities is required). Improved oversight would allow Medicare and Medicaid to require accessibility standards as a prerequisite to physician payment. Failure to provide access for patients with disabilities would be treated as a form of fraud. Currently, clinicians who commit Medicare or Medicaid fraud have payments from all federal insurance programs frozen until the issue is resolved.

While increased enforcement through payment and accreditation mechanisms is unlikely to be popular with clinicians, it may be necessary if both research and patient narratives continue to describe substandard care for patients with disabilities. Rather than wait for new and potentially harsh penalties to be implemented, we suggest that clinicians take action now and begin to implement the recommendations of providing physical and programmatic access for all patients with mobility disabilities. At the very least, Dr. Iezzoni's study should remind us that we as clinicians have an ethical duty to try to improve the experience and quality of care for our patients. On entering this profession, we promised our patients that, first and foremost, we would do no harm. For patients with mobility impairment, we are failing in this promise.

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