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Challenges with Non-descriptive Compliance Labeling of End-Stage Renal Disease Patients in Accessibility for Renal Transplantation

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Abstract

Non-descriptive and convenient labels are uninformative and unfairly project blame onto patients. The language clinicians use in the Electronic Medical Record, research, and clinical settings shapes biases and subsequent behaviors of all providers involved in the enterprise of transplantation. Terminology such as *noncompliant* and *nonadherent* serve as a reason for waitlist inactivation and limit access to life-saving transplantation. These labels fail to capture all the circumstances surrounding a patient's inability to follow their care regimen, trivialize social determinants of health variables, and bring unsubstantiated subjectivity into decisions regarding organ allocation. Furthermore, insufficient Medicare coverage has forced patients to ration or stop taking medication, leading to allograft failure and their subsequent diagnosis of *noncompliant*. We argue that perpetuating non-descriptive language adds little substantive information, increases subjectivity to the organ allocation process, and plays a major role in reduced access to transplantation. For patients with existing barriers to care, such as racial/ethnic minorities, these effects may be even more drastic. Transplant committees must ensure thorough documentation to correctly encapsulate the entirety of a patient's position and give voice to an already vulnerable population.

INTRODUCTION

Over the past decade, a renaissance of patient-centered language has emerged, transforming terms such as "drug addict" and "diabetic" to "person who uses drugs" and "person with diabetes." Such language helps recast how healthcare teams, the public, and patients view their circumstances. Placing a person's humanity before their condition or diagnosis lends some much-needed context and empathy. Modern medicine is continuing to adapt, fixing past shortcomings, and shaping the future of clinical care. The enterprise of End-Stage Renal Disease (ESRD) care and kidney transplantation is no different. Here, we argue that patient-centered language is critical in transplantation as conscious and unconscious biases have more significant consequences when brought into decisions regarding organ allocation. Transplantation poses a distinct challenge, requiring a difficult balance between patient equity and utility when deciding how to ration a limited number of organs to an ever-growing list of candidates. When making these decisions, it is vital to understand each patient's circumstance completely rather than rely on the convenient labels that have been perpetuated through decades of an evolving care system. The United Network for Organ Sharing (UNOS) database reports over 11.7 million instances where a patient was temporarily inactivated from the waitlist due to the use of non-informative language such as "work-up incomplete" and "medical noncompliance." These reasons account for over 70% of all inactivations between 2006-2020. Such labels create bias in a field that requires a holistic evaluation of an ESRD patient's viability for life-saving transplantation.

HOW DID WE GET HERE?

The term *compliance* was initially used to describe patients' obedience to physician advice. By the 1970s, *medical noncompliance* was used more narrowly to characterize patients unwilling or unable to take their prescribed medication. The newer term *nonadherence* offers a slightly less patronizing perspective, yet both terms contribute to a power imbalance between patient and physician[1]. While these terms are

known to be potentially harmful, more neutral labels have surfaced in the field of nephrology and renal transplantation, such as *work-up incomplete*. We argue that the use of non-descriptive language fails to capture a patient's real-world experience.

Non-descriptive terminology, in this context, is defined as a single word or phrase that does not correctly describe the totality of a patient's circumstance. All labels are fundamentally flawed in their ability to describe situations in detail. However, reliance on non-specific labels denies due process to the patient and overlooks potential mitigating factors in the patient's situation. Importantly, replacing terms such as *nonadherence* or *noncompliance* with another label would be futile, further perpetuating the same inequities left by their use. Historically, as reviewed in Laederach-Hoffman and Bunzel, in 1997, The Royal Pharmaceutical Society of Great Britain recommended using the term "nonconcordance" to replace *noncompliance* without alluding to the systemic hierarchy in medicine[2]. Although the term was never adopted, it demonstrates a pattern of inappropriate change.

LIMITATIONS WITHIN KIDNEY TRANSPLANTATION

In reviewing the UNOS database, *work-up incomplete* accounted for 178,578 patients being inactivated from the waitlist between 2006-2020. Although *work-up incomplete* is not stigmatizing, the term provides no added information besides the lack of data or patient-derived follow-up. We argue that labels, such as work-up incomplete, generalize patient situations. The more valuable EMR information answers, "what is incomplete" and, equally important, "why is it incomplete." In situations where work-up incomplete is a label accurately used to describe missing patient information, such as a colonoscopy, the EMR should explicitly describe what is incomplete. A comprehensive EMR note may read, "work-up incomplete due to missing updated colonoscopy, as the patient is unable to afford transportation to the center." Thorough descriptions impart much-needed context and empathy with the hope of changing the

treatment approach or plan. A culture change in patient documentation could expand the involvement of other care team members in addressing the needs of each patient.

THE PROBLEM

Terminology that attempts to describe a patient's inability to follow the care regimen does not account for social determinants of health such as medication cost, lack of family support, insufficient information, overwhelming numbers of medications, and others[2]. Not only are these nonspecific labels unable to encompass socioeconomic factors, but they also lend to dangerous provider assumptions that once a patient is labeled *noncompliant*, they will remain *noncompliant*. Understanding why patients receive these labels is essential to providing patient-centered healthcare that improves access and gives patients the care they deserve. Still, *noncompliance* remains a diagnosis in the Electronic Medical Record (EMR). While newer iterations of the International Classification of Diseases (ICD-10) coding system provide some ability to report additional descriptors, as seen in **Table 1**, these stigmatizing labels continue to inadequately portray patients' circumstances. Additionally, labeling has different consequences in different contexts. While the convenience of nonspecific terminology may offer some practicality in acute settings, convenience offers less value in deliberative processes such as organ allocation in ESRD.

These labels are also frequently used in the academic literature across various transplantation journals when characterizing the well-understood association between inconsistencies in taking medication and poor graft survival. Since 2000, 193 papers on PubMed have titles that reference *noncompliance* terminology within transplantation. These studies have found that patients who struggle to follow their immunosuppression regimen have an elevated risk of late allograft failure[2,3]. As a result, institutional transplant committees use patient *noncompliance* as a criterion for waitlist delisting. According to the UNOS Database, 7,852 patients have been temporarily inactivated from the waitlist due to *medical noncompliance* between 2006 and

2020. Although it is not policy to preclude a patient from transplantation indefinitely once inactivated for these reasons, the added barrier to transplantation places an unfair toll on patients and their caregivers. When making decisions regarding waitlist modifications, patient records should reflect, in granular detail, the reasons for their inability to adhere to their care plan. Furthermore, patients should have the ability to contest these labels.

INSUFFICIENT INSURANCE COVERAGE

Insufficient Medicare coverage of immunosuppressive medication highlights an extenuating circumstance where nonspecific labels such as *noncompliant* do not accurately encapsulate a patient's behavior. In 2020, 59% of all adult kidney transplant recipients in the United States relied on Medicare as their primary insurance provider[4]. Unfortunately, since 1993, Medicare has only covered immunosuppressive drugs for the first 36 mo following a kidney transplant in patients under 65 years old without work-related disabilities[5]. This abrupt cutoff of coverage forces financial burden onto many patients leading to the rationing or discontinuation of their medications and eventual allograft failure. In addition, patients who remained consistent with their immunosuppressive regimen until the expiration of their prescription coverage are mischaracterized as *noncompliant*. As a result of persistent advocacy, the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2020 has made lifelong Medicare coverage of immunosuppression a reality in 2023[6]. Regardless, for patients who have already stopped or rationed their medications due to inadequate coverage, the damage is done.

Arguments for using non-descriptive labels, such as *noncompliance* or *nonadherence* stipulate that their use adequately reflects situations where patients are actively unwilling to follow the care regimen. While clinicians and researchers may believe that the selective use of these labels is justified, this opens the door for subjective and unfair labeling across the entire organ transplant recipient

population. Non-descriptive language trivializes the reasons for *noncompliance* with no regard to medical and social factors that led to such behavior. The indiscriminate use of these labels without adequate explanation of the inability or unwillingness to follow the care regimen adds nothing but unsubstantiated subjectivity to decisions regarding life and death.

STIGMATIZING LANGUAGE AND RACIAL BIAS

Recent literature reports that EMR notes regarding Black patients are more likely to include stigmatizing language when compared to notes regarding White patients[7]. This supports the findings of many studies which indicate that healthcare providers hold conscious or unconscious biases toward people of color[8]. Transplant clinicians are no exceptions, as racial discrimination has manifested throughout multiple areas of the renal transplant process. Compared to White patients, Black patients are less likely to be referred, evaluated, and approved for transplant, more likely to be excluded from the waitlist, and ultimately experience decreased rates of transplantation and retransplantation[9,10]. We argue that the increased use of stigmatizing language in minority populations plays a role in their diagnosis as *noncompliant,* reducing their access to transplantation.

CONCLUSION

Non-descriptive labels in transplantation are unfortunately common and unfairly project blame onto ESRD patients. Labels such as *noncompliance, nonadherence,* and *work-up incomplete* fail to accurately portray ESRD patients awaiting transplantation. The grave nature of the situation is compounded by their prevalence in literature and patient care over the last two decades. Furthermore, the implementation of the ICD-10 coding system has streamlined portions of an overburdened EMR, yet it incompletely describes ESRD patients with barriers to care. Minority populations and those who rely on Medicare already experience existing

challenges and deserve comprehensive language the most. National organ sharing networks should incorporate strict delisting criteria for prospective transplant recipients, eliminate non-descriptive terminology such as *noncompliance,* and work to limit bias and subjectivity throughout the allocation process. We urge providers, regardless of specialty, to report patient information in granular detail to ensure the entirety of the patient's circumstance is captured. We recognize the burden these actions place on clinicians. However, the convenience of using non-descriptive labeling grossly mischaracterizes patients' behavior, limiting their access to life-saving transplantation.

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