

**MEDICAL EDUCATION: PEER-REVIEWED ARTICLE**

**Applying a Health Equity Lens to Better Understand End-of-Life Prognostication**

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**Abstract**

Racial and ethnic inequity exists throughout the lifespan, including at the end of life (EOL). Although prognostication is inherently fraught with uncertainty, many underrepresented minorities get prognoses that are overly optimistic, which can exacerbate inequity by depriving patients of details needed to make informed decisions and plan for EOL care. This article applies a health equity lens to facilitate better ethical and clinical understandings of how to care for patients of color more equitably at the EOL.

**Prognostication at the End of Life**

“How much longer do I have?” is one of the most crucial and ethically challenging questions posed by patients. End-of-life (EOL) care has become an increasingly important topic in medical practice in light of population aging, growing diversity, and complexities presented by the COVID-19 pandemic. Prognostication fundamentally informs EOL care and is integral to the process of informed decision-making.<sup>1,2</sup> A prognostic message has tremendous medical and psychosocial value, as patients and their loved ones use this information to guide treatment pathways, advance care planning, and decisions on how to live a meaningful life at the EOL. It is also important to note that a disproportionate amount of resources and care are utilized at the EOL and that inaccurate predictions of prognoses can result in a significant financial burden for patients and their families.<sup>3</sup> Clinicians are responsible for **communicating to patients** both a prognosis and the possibility that their prognosis may be inaccurate. Effective prognostic messages can improve trust and patient satisfaction and alleviate uncertainties and anxieties at the EOL, with the ultimate goal of helping patients attain goal-concordant EOL care.<sup>4,5</sup> Although prognostication is inherently fraught with a degree of uncertainty, underrepresented minorities (URM) receive prognostic messages that are disproportionately overly optimistic, which has implications for equitable EOL decisions and care.<sup>6,7</sup> These inaccuracies in

prognostication are poorly understood and inadequately discussed by the health care and ethics communities.

### **Prognostic Inequity**

Inaccurate and overly optimistic prognoses that influence decisions to pursue intensive treatment at the EOL can cause harm by depriving patients of informed decision-making and EOL planning. A 2019 opinion piece in the *New York Times*, written by a critical care and palliative medicine clinician, explored the reality of African American patients receiving too little care during life and too much care during the end of life.<sup>8</sup> While there are many factors that might contribute to EOL inequities, the author referred to more intensive care at the EOL for URM as a “temporary salve,” an attempt to mitigate the guilt and fear a clinician feels as part of a racist, oppressive health care system that many patients distrust.<sup>8</sup>

Justice with regard to resource allocation cannot be achieved in the remaining hours, days, or months of life in the face of structurally imposed harm over a lifetime. Qualitative research shows that URM’s lifetime experience of structural racism and bias in health care settings may lead to their underuse of EOL care services because they cannot conceptualize nonaggressive EOL care and often fear that aggressive EOL therapies will be withheld because of their race.<sup>9</sup> Clinicians’ failure to understand the compounded and accumulated **structural inequities** that contribute to patients’ loss of confidence in the health care system and underuse of EOL care can create barriers to effective communication and accurate prognoses.<sup>10</sup> These complexities may in part explain why prognostic communication occurs less frequently among URM patients.<sup>6</sup> Other research shows that overly optimistic prognostic messages are associated with less and later hospice use by minority patients, which is not supported by their stated EOL care preferences,<sup>7</sup> suggesting that overly optimistic diagnoses may lead to misalignment of treatment with patients’ EOL preferences.<sup>7</sup> Life-prolonging measures may, in fact, undermine patient values and engender undue financial distress for patients and their families.<sup>11</sup>

There are other barriers to accurate prognostication. Physicians’ limited understanding of the social and structural drivers that influence patient outcomes could distort the context in which they formulate prognoses. Furthermore, prognostic evidence is informed by clinical trials with limited racial diversity, perpetuating prognostication inaccuracy and norms that fail to reflect the realities and experiences of diverse patient populations.<sup>1</sup> Such biased prediction modeling may be exacerbated in the future with increased use of artificial intelligence, which fundamentally relies on data that might not be representative.<sup>12</sup>

### **Rectifying Prognostic Inequity**

Despite the limited literature on racial and ethnic disparities in EOL prognostication, existing evidence of health care bias and medical mistrust can be used to inform prognostication strategies and future directions for the medical community.<sup>8,13</sup> For example, enhancing trust and trustworthiness in

health care settings by giving consideration to patients' realities throughout all life stages is critical to improving EOL care for URM.<sup>11</sup> In particular, the application of a life-course perspective—which posits that health outcomes are shaped by earlier exposures to physical, environmental, and psychosocial influences and that these cumulative exposures contribute to health disparities—can advance health equity.<sup>13</sup> Beyond building trust, justice requires advocacy at the systemic level for structurally appropriate health care policies, accessible patient education, and more equitable, evidence-based practices.<sup>14</sup> In addition to applying a life-course perspective, justice entails providing URM with information and adequate prognostic knowledge by engaging them in patient-centered goals-of-care conversations and participation in EOL decision-making.

*Systemic level.* At a systemic level, the medical community should consider factors influencing inequitable access to care. For example, Medicare and Medicaid are largely responsible for inequitable access to EOL care for low-income URM. Indigenous and Native American patients frequently do not have access to EOL care because many tribal health organizations are unable to meet Medicare and Medicaid criteria for hospice services.<sup>14</sup> The expansion of available EOL resources would combat structural discrimination against URM and, by extension, alleviate disparities that skew prognostication and overall health outcomes for patients. Policy makers and clinicians should also prioritize quality of EOL care to meet the complex needs of URM. Along with these changes, mitigating prognostication disparities requires an expansion of current **perceptions of EOL care** among clinicians and their professional communities.

Furthermore, better communication about comprehensive EOL care could also help patients make more informed EOL decisions that align more closely with their values and preferences. For example, integrating religion and spirituality into EOL care directly aligns with the practice recommendations of the National Hospice and Palliative Care Organization.<sup>15</sup> While data show that Black and Hispanic patients disproportionately receive care from for-profit hospices that provide poorer quality of care, spiritual support should ideally be provided by entities that are preferred by patients, such as faith-based partners from their respective communities rather than outside vendors.<sup>16</sup> Furthermore, **culturally responsible interventions** entail diversifying the audience to whom EOL care services appeal, which can be achieved by strengthening social support through a diversified, multilingual workforce that includes URM. This diversification of perspectives would allow for the optimization and individualization of EOL care. It would also enhance understanding of the intersectional complexities<sup>17</sup> that we argue influence prognoses in URM, thereby potentially increasing accurate prognostication.<sup>17</sup>

*Individual level.* To decrease bias and prognostic inaccuracies at the individual level, clinicians can utilize existing prognostication scoring tools to increase objectivity and potentially minimize disproportionate optimism.<sup>18</sup> Since these prognostic tools may contain their own biases and are calibrated to inpatient settings for patients with malignancies, developers and individual users should

modify these tools by incorporating social determinants of health into their algorithms, and predictions should be modulated by the human insight of the clinician.<sup>18,19</sup> Further research is also needed to investigate disparities in prognostication across various URM groups. For example, there is a paucity of data on Middle Eastern or transgender patients experiencing prognostication disparities at the EOL.<sup>20,21</sup> Studies should also focus on aspects of identity that might influence prognosis, such as non-heterosexual and non-cisgender identity, homelessness, and other socially marginalized identities that are associated with the poor delivery of health care and adverse health outcomes.

### Conclusion

At all stages of life, URM are confronted with health and health care inequities. The medical community is ethically obligated to recognize, investigate, and combat this stark injustice. Improving prognostication across populations is an integral part of addressing persistent health disparities and providing appropriate care to URM. Advances in advocacy, medical sciences, predictive tools, and workforce diversity are necessary to achieve health equity for URM within and beyond the realm of prognostic communication. Furthermore, while this discussion focuses on EOL prognostication, clinicians have an ethical and professional duty to provide respectful and equitable care throughout all stages of life. Indeed, if death is often considered a vessel for lessons on life and living, the life course proves to be an illuminating lesson on death, dying, and inequities at the EOL.

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