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Actionable Solutions to Achieve Health Equity in Chronic Liver Disease

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Abstract

There are well-described racial and ethnic disparities in the burden of chronic liver diseases. Hispanic persons are at highest risk for developing nonalcoholic fatty liver disease, the fastest growing cause of liver disease. Hepatitis B disproportionately affects persons of Asian or African descent. The highest rates of hepatitis C occur in American Indian and Alaskan Native populations. In addition to disparities in disease burden, there are also marked racial and ethnic disparities in access to treatments, including liver transplantation. Disparities also exist by gender and geography, especially in alcohol-related liver disease. To achieve health equity, we must address the root causes that drive these inequities. Understanding the role that social determinants of health play in the disparate health outcomes that are currently observed is critically important. We must forge and/or strengthen collaborations between patients, community members, other key stakeholders, health care providers, health care institutions, professional societies, and legislative bodies. Herein, we provide a high-level review of current disparities in chronic liver disease and

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describe actionable strategies that have potential to bridge gaps, improve quality, and promote equity in liver care.

Keywords

Health Equity; Quality Improvement; Social Determinants; Health Disparities; Diversity; Chronic Liver Disease

According to the National Institute for Minority Health and Health Disparities,[1] health disparities are defined as health differences that adversely affect disadvantaged populations, reflected by higher disease burden, greater prevalence of risk factors, higher degree of disease-specific symptoms, and/or increased or premature mortality. Although sometimes used interchangeably, health disparities and health equity are not synonymous. “Health equity is the ethical and human rights principle that motivates us to eliminate health disparities, which are key differences in health or its key determinants (such as education, safe housing, and freedom from discrimination) that adversely affect marginalized or excluded groups. Disparities in health and in the key determinants of health are the metric for assessing progress toward health equity.”[2] Health disparities are driven by a multitude of factors that interact to lead to differential outcomes; these factors are highlighted in Figure 1, adapted from the National Institute for Minority Health and Health Disparities Health Disparities Research Framework.[3] Despite the significant body of literature describing disparities in patients with chronic liver disease (CLD) over the past 2 decades, little progress has been made toward understanding root causes of disparities and achieving health equity.

Herein, we discuss disparities in CLD and highlight strategies that can reduce pervasive inequities. We focus on key subgroups who are vulnerable to disparities based on race, ethnicity, sex, and geography, emphasizing differences that arise from structural, societal, community, neighborhood, and institutional factors. Other marginalized groups, such as sexual gender minorities, are not covered, mostly because of limited data on specific factors driving disparities. Similarly, we exclude autoimmune diseases given limited available data relative to other CLDs. We acknowledge existing gaps in evidence and recommend future directions to bridge these gaps.

Racial and Ethnic Disparities in Chronic Liver Disease and Why They Exist

Race, a social construct, is related to an individual’s or a group’s identity that is linked to visible and stereotypic attributes, such as skin color and hair texture. Ethnicity categorizes individuals based on shared culture, language, and traditions.[4] There are widening racial and ethnic disparities across many CLDs and their outcomes.[5,6] For example, Black patients have higher risk of liver-related hospitalizations than White patients. In a retrospective study of patients with cirrhosis, Black patients were hospitalized an average of 6.1 times over a 5-year period, followed by 4.5 times in Asian and Pacific Islander (API), 3.4 in Hispanic, and 3 times in White patients ($P = .01$).[7] Black or API patients also have higher in-hospital mortality rates than whites (7.7% and 8.3% vs 7.3%, respectively).[8] Age-adjusted liver-related mortality is 50% higher for Hispanic than non-Hispanic White persons.[9]

Individual, interpersonal/institutional, community, and societal characteristics interact to drive existing racial and ethnic disparities (Figure 1). At the individual biologic level, Black, API, and Hispanic persons are disproportionately affected by risk factors leading to CLD, such as hepatitis C virus (HCV), hepatitis B virus, alcohol use, or nonalcoholic fatty liver disease (NAFLD).

Using the framework provided, one can conceptualize how factors converge to increase CLD burden in minority populations. As an example, excess NAFLD burden in Hispanic populations occurs at the intersection of individual health and family behaviors, community norms, health literacy, and biologic traits, such as genetic susceptibility through *PNPLA3* polymorphisms.[10] Also, NAFLD prevalence differs significantly within Hispanic persons (eg, Central and Mexican Americans have higher prevalence than South Americans, Dominicans, and Cubans).[11] Among other factors, this could be caused by differences in biology, acculturation, employment, and access to financial resources. Similarly, NAFLD prevalence in Asian populations is rising because of multiple converging factors.[12,13] Using the proposed framework, one can dissect and understand determinants in disparities of other CLDs.

A multitude of data highlights racial/ethnic disparities in the prevention, diagnosis, and treatment of CLD. The Racial and Ethnic Approaches to Community Health across the US (REACH US) study found notable differences in hepatitis B virus screening rates across racial/ethnic groups.[14] Specifically, among 53,896 minority respondents, API individuals had the highest screening rates (42.5%), followed by Black (40.4%) and Hispanic (35.6%) individuals.[14] Of 1235 people with chronic hepatitis B virus, only 33% had seen a provider, with significant variation in treatment rates from 48% in API patients, 51.3% in Black, and 66.7% in Hispanic patients.[14] Similar disparities exist for HCV. Although Black and Hispanic individuals have disproportionately higher HCV prevalence[15] and associated complications, Black patients had 21% lower adjusted odds of receiving direct-acting antivirals than Whites in a Veterans Affairs (VA) study.[16] Similar treatment disparities were found in Medicare and commercially insured populations.[17,18]

Liver transplantation is the only lifesaving modality for patients with end-stage liver disease; however, access is limited for racial and ethnic minorities. Both Hispanic and Black patients are underrepresented on the transplant waiting list,[19,20] and this disparity worsened during the COVID-19 pandemic.[21] Hispanic patients are 23% more likely to be removed from the waitlist because of mortality compared with White patients (subdistribution hazard ratio, 1.23; 95% confidence interval [CI], 1.13–1.34).[22] Black patients with end-stage liver disease are least likely to be listed for transplant; the listing to death ratio was 0.30 in Black patients, compared with 0.41 for White and Hispanic patients and 0.79 for API patients ($P < .000$)1.[23] Minorities also receive disproportionately fewer living donor liver transplants.[24]

Racial and ethnic disparities extend into other feared complications of CLD. Black and Hispanic patients with hepatocellular carcinoma (HCC) are consistently diagnosed at advanced cancer stage,[25,26] which affects treatment eligibility. Even with early stage HCC, Black patients receive treatment less often and have 12% increased mortality compared with White patients (hazard ratio [HR], 1.12; 95% CI, 1.03–1.20).[27] Black patients receive transplant for HCC at approximately half the rate of White and Hispanic patients.[25,28] Disparate receipt of treatment exacerbates survival differences.

Social determinants of health (SDOH), “nonmedical factors such as income, health insurance, education, discrimination, and the quality of the places where people live, work, learn, and play, which influence health,”[2] drive many disparities in CLD prevalence, progression, and treatment. Racial/ethnic minorities are more likely to have lower socioeconomic status and be underinsured,[29] limiting access, including treatment of etiologic risk factors. The frequency, morbidity, and mortality from CLDs and related complications are higher in persons with low socioeconomic status.[30,31] For example, patients with cirrhosis from low-income neighborhoods have significantly higher risk of HCC and death than patients from high-income neighborhoods.[32] This difference was most notable in Black and Hispanic patients. Thus far, most disparities and equity research has focused on describing individual and interpersonal levels of influence (Figure 1), rather than understanding or intervening at the community level.

Interpersonal-level factors that operate at the interfaces of patient-family or patient-health system organization could influence disparities. Social support[33,34] and household situation could contribute to disparities in CLD, because they influence self-care, health behaviors, and treatment adherence.[33,35] Differences in experiences with the health care system may result in medical mistrust, which could influence health behaviors.[36] In 1 study, Black patients with HCC had the highest levels of medical mistrust using the Group Based Medical Mistrust Scale, followed by Hispanic, then White patients.[37] A cross-disciplinary systematic review of 15 studies showed that implicit bias was significantly related to patient-provider interactions and treatment decisions.[38] Lack of diversity in care teams, interpersonal racism,[39] and implicit bias[40] may contribute to disparities in listing and receipt of transplant. Although not previously examined within CLD, provider knowledge and patient-provider race concordance could be important given their effect in other diseases.[41]

Many CLD risk factors could result from neighborhood factors including community-level prevalence of HCV, diabetes, obesity, alcohol use, and smoking. Other community attributes and SDOH that could influence patients’ experiences and prognoses and differ by race/ethnicity include differences in transportation and number and quality of health care facilities.[42] Access to transportation may impact ability of patients to be listed for transplantation.[43] Segregation and number and quality of health-promoting/impairing factors (eg, food markets, liquor stores, food deprivation) could also be important in explaining racial/ethnic disparities. Food insecurity[44] and diet quality[45] have only been studied in association with NAFLD.

Gender Disparities in Chronic Liver Disease and Why They Exist

Disparities between women and men with CLD are well-documented at all stages of liver disease. Many result from biologic sex differences that arise from differential effects of sex chromosomes and sex hormones. Herein, we focus on gender inequities, that is, differences that arise from sociocultural or health care system structural factors.

Gender inequities are perhaps most apparent with alcohol-associated liver disease. Although some of these are related to individual biologic differences (eg, women are more susceptible to hepatotoxic effects of alcohol at lower doses of alcohol than men), factors at the interpersonal and health system levels also play a role. Women were 16% less likely to receive a face-to-face visit and 11% less likely to be prescribed a Food and Drug Administration–approved relapse prevention medication than men.[46] Women had a 21% lower adjusted odds of HCV screening than men,[47] despite increasing HCV rates among women of child-bearing age.[48] Emerging evidence suggests that implicit bias around provider perception of women's suitability for transplant may result in decreased transplant access.[40]

Societal and policy level factors drive gender-based disparities. There are several documented areas of sex-based inequities in liver transplantation related to the national allocation/distribution system.[49,50] First, allocation by the Model for End-Stage Liver Disease (MELD) score consistently underestimates renal dysfunction in women because of use of serum creatinine (rather than estimated glomerular filtration rate).[51,52] This underestimates a woman's risk of death and results in lower waitlist prioritization by 1–2.4 fewer creatinine-derived MELD points than a man with similar estimated glomerular filtration rate. Second, lack of size-appropriate livers leads to up to 17% lower transplant rates for women.[50,53,54] Transplantation of organs requires some degree of size matching; a greater proportion of liver donors are men who are, in general, substantially taller than waitlisted women.[53,55]

Geographic Disparities and Why They Exist

Geography contributes to health disparities in CLD. There is significant interstate variability in liver disease mortality, ranging from 6.4 to 17.0 per 100,000, with higher rates in the South and the West.[56] Patients in the West also have a significantly lower probability of being referred (HR, 0.70; 95% CI, 0.53–0.93), being wait-listed (HR, 0.48; 95% CI, 0.36–0.64), and undergoing transplant (HR, 0.50; 95% CI, 0.34–0.74) than patients in the Northeast.[57] Patients with HCC living in rural versus urban areas experience an 18% higher odds of late-stage diagnosis, 12% decreased odds of receiving treatment, and 9% increased risk of HCC stage-specific mortality.[58] These disparities likely stem from limited physical access to health care (including transplant centers), but also from differences in physical environment, lifestyle, culture, and state policy.

An individuals' travel time to a transplant center is strongly associated with death: compared with patients living <60 minutes away from their transplant center, those living >60 minutes away experienced approximately 30% increased risk of waitlist mortality and 10% reduced likelihood of transplantation.[59] Despite efforts implemented in 2020 to reduce long-standing geographic disparities in liver transplantation rates because of arbitrary donation service area boundaries, significant variation in access to transplantation by geographic region remains.[60]

Community-level factors can predict geographic HCC incidence and mortality in patients with cirrhosis.[61,62] For example, geographic differences in HCC incidence were correlated with state-level obesity and inversely correlated with state-level physical activity.[63] At the societal and policy level, states with stronger policies designed to curb alcohol consumption (eg, alcohol excise taxes, regulation of location or time of sales) have an 11% lower alcohol-associated cirrhosis mortality rate than other states.[64] Statewide differences in Medicaid expansion contribute to differences in the proportion of uninsured adults and treatment uptake for HCV with subsequent geographic differences in end-stage liver disease mortality.[65]

Strategies to Bridge Disparities in Chronic Liver Disease

Although many studies have described disparities in CLD, few describe interventions to close these gaps. We review key initiatives that either demonstrated early success in reducing disparities or hold promise to serve as foundational efforts to bridge gaps. Using tele-mentoring, Project ECHO dramatically increased access to HCV treatment for geographically challenged patients across rural New Mexico,[66] thereby demonstrating that equity could be achieved with forethought and knowledge of unique barriers. This approach has been adopted by several health systems to increase the reach of their services. The Specialty Care Access Network-ECHO[67] has allowed the VA to deliver quality liver-focused care, from HCV treatment to HCC management to triage for liver transplant to geographically dispersed population.[68] The effectiveness of ECHO-like models should be examined in other populations and non-VA health care systems.[69]

Other ongoing efforts could serve as platforms to test and implement strategies to reduce CLD disparities. The Cirrhosis Quality Collaborative (CQC), supported by the American Association for the Study of Liver Diseases,[70] is a multisite Learning Health Network that combines quality improvement and research to improve care and treatment outcomes. The CQC aims to bridge gaps in care by allowing teams from different institutions to collectively identify and implement efforts that will lead to continuous quality improvement in the care of populations with cirrhosis. As such, CQC could lend critical infrastructure to test interventions that reduce undue variations in care by gender, race, ethnicity, socioeconomic status, and/or other nonclinical factors. The VA Hepatic Innovation Team Collaborative uses systems redesign methods and population health with the goal of improving care for Veterans with cirrhosis approaches. The collaborative developed an Advanced Liver Disease dashboard to monitor important metrics and identify patients and/or sites that are not meeting metrics. The Hepatic Innovation Team was able to leverage local resources to overcome potential barriers in access to provision of care across sites.[71]

Single-site initiatives could serve as models that guide local efforts to improve care and reduce inequities. After a needs assessment, Project Liver Health categorized CLD patients into 7 severity stages and redesigned a clinical service line to include a viral hepatitis center, a multi-disciplinary ambulatory cirrhosis center, and a rapid access postdischarge clinic.[72] Tapper and Parikh[73] provide a blueprint for how to select process measures, patient-reported outcomes, and clinical outcomes and describe use of dashboards for monitoring. Simpler approaches, such as standardized “smartphrases” and note templates, could facilitate systematic and consistent data capture for subsequent analysis of disparities.

Solutions to Address Chronic Liver Disease Disparities

The previously described initiatives were not specifically designed to improve equity, underscoring the need to develop strategies with the primary goal of closing disparity gaps. Strategies that focus on improving quality as a sole means to improve disparities and achieve equity are inadequate unless intentionally targeted to improve care for the most vulnerable populations.[74] Untargeted interventions could worsen disparities because uptake of such initiatives might disproportionately benefit populations with a preexisting advantage. We discuss key strategies and efforts that we believe could help to bridge these chasms. Others are detailed in Figure 2.

Individual- and Interpersonal-Level Solutions

Identify and Correct Implicit Biases

As health care providers, we need to understand our own biases that influence equity of care delivery. In addition to ongoing introspection to examine for biases, health care providers should seek opportunities to train on health disparities and health equity through the National Institute on Minority Health and Health Disparities and the Association of American Medical Colleges Center for Health Justice.[75] A variety of tests aimed at identifying one's own implicit biases[76] is found at https://implicit.harvard.edu/implicit/takeatest.html.

Increase Inclusion and Achieve Equity in Research

Despite stark racial and ethnic differences in CLD prevalence, minority patients continue to be underrepresented in CLD clinical trials.[77] As researchers, we must be aware of barriers to equitable representation, which are multifaceted and include socioeconomic challenges, lack of access, resources for patients with limited English proficiency, and failure to understand patients' cultural beliefs or establish trust. Dedicated funds for culturally relevant translation of study materials and consistent use of interpreters may help overcome language barriers.[78] We must assess health literacy and appropriately tailor conversations about research and informed consent.[79] Strategies to overcome mistrust include validation of participant concerns, careful explanation of the approval process, frequent communication, and hiring of diverse research staff. It is imperative that we engage patients and other stakeholders in the design and conduct of clinical research to ensure that their questions are being answered and needs are being met.[80] Investigators should use inventive approaches to address financial constraints, such as need-based stipends.

Institutional-Level Solutions

Systematic Measurement of Social Determinants

Many disparities in the prevalence, progression, and treatment of CLD are driven by SDOH. Routine collection of SDOH during clinical practice allows for identification of vulnerable patients and populations at greatest risk of developing adverse disease outcomes. These data also provide increased insight into the lived experiences of patients[81] and would allow the health care teams to ascertain patients' needs. For example, there are high rates of financial burden among CLD patients and their caregivers.[82] Although many health care institutions collect some SDOH data, data collection is neither standardized nor routinely incorporated into care. Institutions and practices should examine how current policies impact patients, based on individual-level SDOH, and how existing or proposed policies might inadvertently contribute to increased disparities. Ongoing analysis of SDOH could guide dedicated efforts to reduce structural racism and improve equity.

Shifting to Patient-Centered Care

Development of a patient-centered specialty practice,[83] which honors patients' preferences, needs, and values, could benefit patients with advanced CLD, those with multiple comorbidities, and/or those at greatest risk to develop complications of CLD. There are substantial barriers to development of an integrated, patient-centered model for patients with CLD and limited data[84]; however, some studies are underway. To achieve equity, institutions must consider how the patient-centered specialty practice may differ in different communities and focus on vulnerable patient populations who experience disparities.

Community-Level Solutions.—Researchers and clinicians should identify local communities at greatest risk for disparate outcomes and identify their institution's or practice's strategy for proposed community outreach. Initiatives that leverage relationships with community organizations have more potential for success. Community stakeholders should be invited to work collaboratively on processes and practices aimed at building trust and increasing access. Practices and institutions should also aim to support initiatives spearheaded by community organizations.

Societal- and Government-Level Solutions

Strategies to Support Health Equity Research

A major barrier to promoting interventions to reduce CLD disparities has been limited funding for disparities and/or health equity researchers. There are lower R01 funding rates for Black applicants, whose topics focus more on community and population health compared with White applicants who focus more on fundamental and mechanistic work.[85] Through several initiatives,[86] the National Institutes of Health has increased efforts to increase scientific workforce diversity[87] and improve gender equity.[88] The Food and Drug Administration Office of Minority Health and Health Equity aims to increase training for diverse clinical trial investigators; identify barriers to clinical trial enrollment in underrepresented populations; improve data collection and quality in these populations; and employ innovative strategies, including training.[89] Researchers should seek educational opportunities aimed at developing the research skills needed to successfully conduct health equity research and establish cross-disciplinary collaborations with experts in health equity and implementation science. Often, health care centers serving underserved populations do not have the infrastructure for clinical research or trials. Achieving health equity requires thoughtful allocation of resources to build the infrastructure required for innovative approaches, such as community-based clinical trials[90] or cohort multiple randomized controlled trials designs.[91] As health care providers, we can influence change by supporting the advocacy arms of our professional societies as they engage with elected officials to influence legislation and policy.

Changes to the National Liver Allocation/Distribution System

Concrete changes in liver allocation may reduce race- and sex-based inequities. The Share 35 policy, implemented in 2013 by the United Network for Organ Sharing, aimed to reduce waitlist mortality, which disproportionately affects women and minorities. Although Share 35 reduced racial and ethnic disparities,[92] it may have worsened geographic disparities.[93] Development of MELD 3.0 is a meaningful step toward "leveling the playing field" between women and men listed for transplant.[94] MELD 3.0 includes female sex and is predicted to offer women a higher chance of transplantation than MELDNa.[94] Regarding candidate-donor size mismatch, prioritizing women for smaller donor livers may offer a practical solution to reduce the gender gap in waitlist mortality.[54,95] A few other examples where clinicians and researchers can seek other opportunities to change policy include local and national policies that affect access to insurance, equitable distribution of health care, and vaccination coverage, among others.

Conclusions

Disparities[96] are pervasive in CLD. Achieving health equity will require deep introspection to identify barriers to equitable care and potential solutions. As the first step, we must acknowledge that unfair social conditions drive inequities in CLD outcomes and work to rectify conditions at the individual, interpersonal, and institutional levels.[97] Neighborhoods play a critical role in our patients' health.[98] Through geospatial approaches we will gain a better understanding of the built environment of our target populations,[99] enabling health care providers and institutions to be better neighbors.[100] More data are needed on factors driving health inequities in other marginalized groups (eg, sexual and gender minorities). Initiatives targeting the overall quality of care can improve equitable delivery of CLD care by reducing undue variations by race, ethnicity, gender, and other SDOH. However, to fulfil their potential promise these initiatives require commitment and intent at the time of program conception. Leveraging the collective power of our professional societies, we can continue to engage with legislators to enact policy change.

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Abbreviations used in this paper:

API	Asian and Pacific Islander

CI	confidence interval
CLD	chronic liver disease
CQC	Cirrhosis Quality Collaborative
ECHO	Extension for Community Health Outcomes
HCC	hepatocellular carcinoma
HCV	hepatitis C virus
HR	hazard ratio
MELD	Model for End-Stage Liver Disease
NAFLD	nonalcoholic fatty liver disease
SDOH	Social determinants of health
VA	Veterans Affairs

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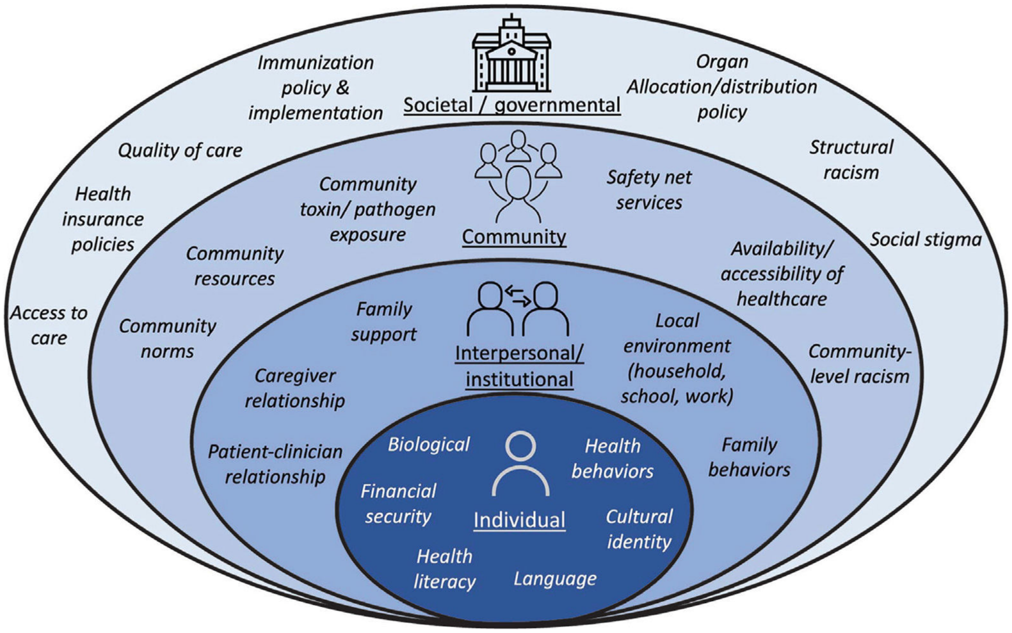
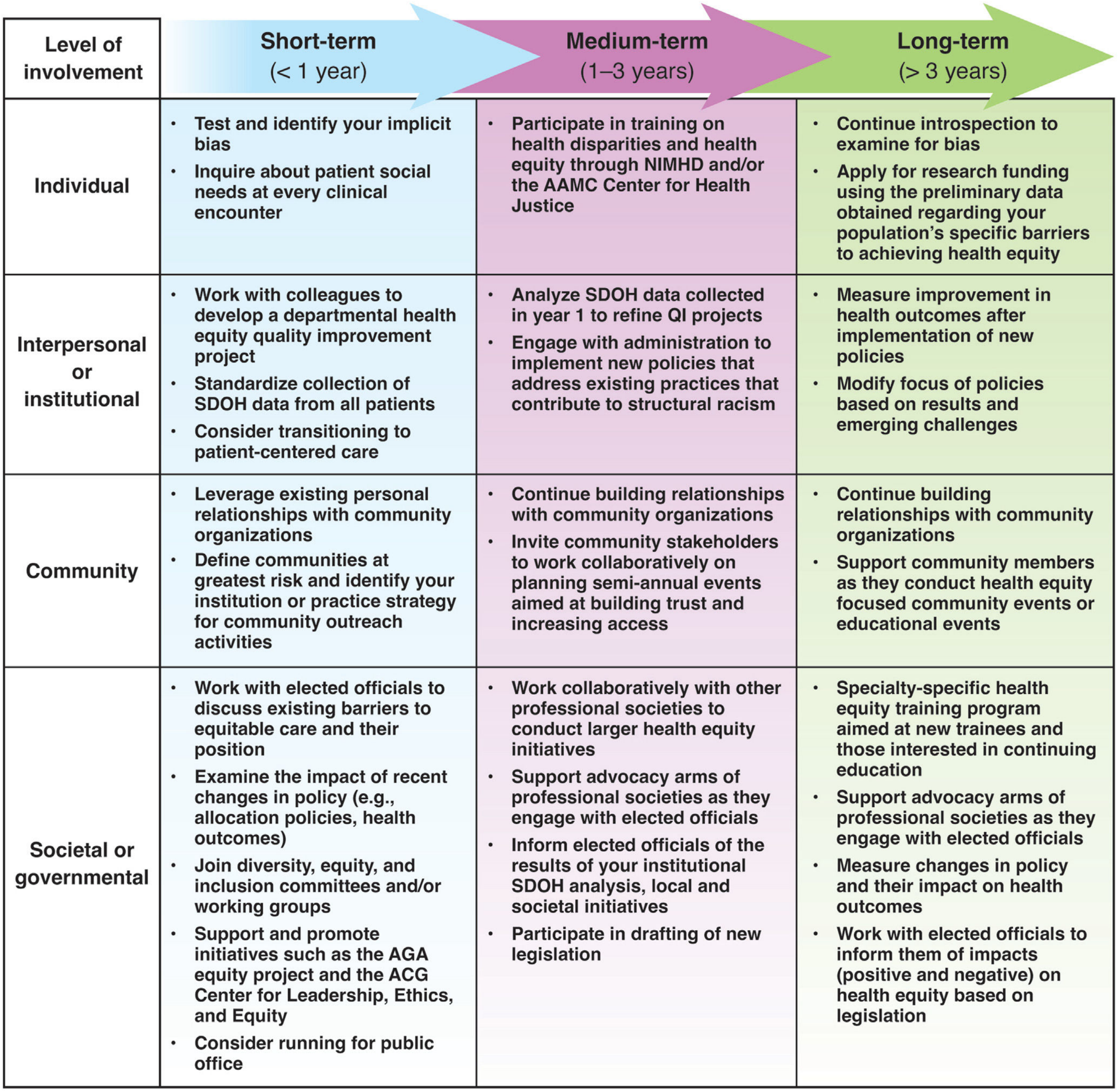


Figure 1.

A research framework for investigating health disparities and inequities in patients living with chronic liver disease. Adapted from the National Institute for Minority Health and Health Disparities framework for research in disparities.



Level of involvement	Short-term (< 1 year)	Medium-term (1–3 years)	Long-term (> 3 years)
Individual	• Test and identify your implicit bias • Inquire about patient social needs at every clinical encounter	• Participate in training on health disparities and health equity through NIMHD and/or the AAMC Center for Health Justice	• Continue introspection to examine for bias • Apply for research funding using the preliminary data obtained regarding your population's specific barriers to achieving health equity
Interpersonal or institutional	• Work with colleagues to develop a departmental health equity quality improvement project • Standardize collection of SDOH data from all patients • Consider transitioning to patient-centered care	• Analyze SDOH data collected in year 1 to refine QI projects • Engage with administration to implement new policies that address existing practices that contribute to structural racism	• Measure improvement in health outcomes after implementation of new policies • Modify focus of policies based on results and emerging challenges
Community	• Leverage existing personal relationships with community organizations • Define communities at greatest risk and identify your institution or practice strategy for community outreach activities	• Continue building relationships with community organizations • Invite community stakeholders to work collaboratively on planning semi-annual events aimed at building trust and increasing access	• Continue building relationships with community organizations • Support community members as they conduct health equity focused community events or educational events
Societal or governmental	• Work with elected officials to discuss existing barriers to equitable care and their position • Examine the impact of recent changes in policy (e.g., allocation policies, health outcomes) • Join diversity, equity, and inclusion committees and/or working groups • Support and promote initiatives such as the AGA equity project and the ACG Center for Leadership, Ethics, and Equity • Consider running for public office	• Work collaboratively with other professional societies to conduct larger health equity initiatives • Support advocacy arms of professional societies as they engage with elected officials • Inform elected officials of the results of your institutional SDOH analysis, local and societal initiatives • Participate in drafting of new legislation	• Specialty-specific health equity training program aimed at new trainees and those interested in continuing education • Support advocacy arms of professional societies as they engage with elected officials • Measure changes in policy and their impact on health outcomes • Work with elected officials to inform them of impacts (positive and negative) on health equity based on legislation

Figure 2.

Practical solutions to address disparities and achieve health equity in the short, medium, and long term.