

**AN ETHICAL CALL FOR EARLY IMPLEMENTATION OF
PALLIATIVE CARE FOR UNDERSERVED HEART FAILURE
PATIENTS**

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ABSTRACT

Heart failure is a disease that affects millions of Americans, but has a disproportionate impact on underserved, minority communities. Over the coming decade, heart failure will become a chronic disease for more Americans as treatments improve, but the disease cannot be cured. Minority populations are, and will continue to be, disproportionately impacted by heart failure due in large part to their increased risk factors, which stem from social and structural determinants of health. Palliative care services offer incredible benefits for patients and caregivers covering a variety of areas, such as goals of care discussions, shared decision-making, and psychosocial support. Providing early palliative care services to underserved heart failure patients offers extra resources to effectively manage their disease and lifestyle in a personalized fashion, and aligns with the urban bioethical principles of agency, social justice, and solidarity.

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CHAPTER 1: INTRODUCTION

In this thesis, I argue in support of the ethical obligation to provide early palliative care services to heart failure patients from disadvantaged communities who have historically had difficulty accessing and navigating the healthcare system. While I explore the utility of broadly implementing palliative care services for heart failure patients, I am particularly focused on offering underserved patient populations access to increased equitable care. During my clinical training as a medical student, I was surprised to learn about the high mortality rate of heart failure. I also participated in a palliative care clerkship. Throughout the rotation, I witnessed many consultations for individuals hospitalized with heart failure exacerbations. A pattern emerged that most of these patients were young, Black individuals who were in their normal state of health prior to admission, although their normal health usually involved managing at least one other comorbidity. Considering my limited knowledge of heart failure and my anecdotal observations of a high proportion of heart failure patients from minority communities at my institution, I began exploring the literature about heart failure demographics and approaches to management. Because my experiences with these patients arose from my time on the palliative care service, I pursued my research through a palliative care lens. Over the past decade, many medical organizations and societies have acknowledged the utility of involving palliative care for managing heart failure. However, there is still debate about when to involve palliative care and which patient populations will benefit most. Importantly, despite widespread acknowledgment of the racial disparities for heart failure prevalence and outcomes, there is a dearth of research and commentary on how

and when to incorporate palliative care services for underserved, minority populations living with heart failure.

My observations and commentary are centered around the discipline of urban bioethics. There are four core bioethical principles: autonomy, beneficence, non-maleficence, and justice. Urban bioethics specifically adds three additional principles: agency, social justice, and solidarity (Reeves, Jones 2022, 497-505). Agency is one's ability to see a complete range of options for a situation and having the capacity to carry out a choice. Social justice requires equitable access to opportunities and acknowledgment of how both disparity and privilege affect any given situation. Solidarity binds two or more stakeholders together. It is imperative to consider individual context when applying these principles. When it comes to health and healthcare, a person's choices are invariably influenced by their social environment. Throughout this thesis, I will highlight these three urban bioethical principles and how they factor into the intersection of heart failure and palliative care for underserved patient populations.

CHAPTER 2: BACKGROUND

Heart failure is a tumultuous disease characterized by unpredictable exacerbations that impact the physical and mental well-being of the patient. Symptoms can include fatigue, cough, shortness of breath, swelling, decreased mobility, and arrhythmias. As the disease progresses, individuals become more deconditioned and commonly rely on others to perform activities of daily living.

As of 2013, data reviewed by *Circulation Research* showed the incidence of heart failure is stable or even decreasing (Roger 2021, 1425). From 2015 to 2018, the American Heart Association estimated the prevalence of heart failure in the United States to be 6 million people (Virani 2021, 651). Despite improved treatments and medication regimens, heart failure cannot be cured. Therefore, prevalence is expected to increase to as high as 8.45% of the population among 65- to 70-year-olds by 2030 (Van Nuys et al. 2018, 405). Despite modern medicine's improved ability to manage heart failure, heart failure mortality remains high with some estimates being 50% within five years of diagnosis (Roger 2021, 1425). However, this number is likely even higher because estimating the number of deaths directly attributable to heart failure is challenging. This is a result of heart failure stemming from an underlying condition, such as coronary artery disease (Ziaean, Fonarow 2016, 6).

Heart failure management places a tremendous financial burden on the healthcare system. In 2010, nearly half of Medicare's costliest patients had heart failure and hospital admissions were the costliest preventable hospitalization for those patients (Ziaean, Fonarow 2016, 14). Not only are heart failure hospitalizations expensive, but they occur

frequently. One study observed hospital readmissions occur in one in four patients with heart failure within thirty days of discharge (Di Palo et al. 2017, 260).

Risk factors for heart failure include hypertension, increased age, female sex, and diabetes (Ziaean, Fonarow 2016, 8). While individuals with hypertension and diabetes are found throughout society, there is a higher prevalence in socioeconomically disadvantaged communities commonly consisting of minority populations. Black individuals have a higher prevalence of cardiovascular risk factors, such as hypertension and diabetes, compared to whites and Hispanics and they are less likely to be prescribed statins for cardiovascular risk reduction (Warraich, Hernandez, Allen 2017, 1279). This puts members of these communities at higher risk for complications, such as heart failure. In fact, the likelihood of hospitalization for heart failure is 50% higher for Blacks and 20% higher for Hispanics compared to whites (Ziaean, Fonarow 2016, 13). Additionally, decreased socioeconomic status is associated with high rates of heart failure when controlling for known cardiovascular risk factors (Ziaean, Fonarow 2016, 6). Unsurprisingly, socioeconomically deprived patients with heart failure are also at greater risk for hospital readmission compared to affluent counterparts (Hawkins et al. 2012, 141).

Not only are members of disadvantaged communities at higher risk for heart failure, but they are ill-equipped to properly manage it once diagnosed. A host of factors, including limited healthcare access, multiple co-morbidities, impaired health literacy, and inequalities in treatment make managing heart failure for these patient populations even more challenging (Hawkins et al. 2012, 144). These factors fall within the social determinants of health. Van Nuys et al. determined Black females have the highest

incidence of congestive heart failure and experience the most difficulty performing activities of daily living after diagnosis (2018, 405-6). The paper adjusted for variables such as age and sex, yet they acknowledge not accounting for social determinants of health, such as greater poverty, poorer access to care, and lower health literacy among Black patients with heart failure when conducting their models. The racial disparities are stark enough when the model only controls for basic demographic data. A model that does account for social determinants of health would likely show an even greater gap in the detrimental effect heart failure has on disadvantaged minority communities.

It is well established that social determinants have an unequal impact on the health of disadvantaged communities. The increased burden of heart failure among Black patients has been documented for decades (Roger 2021, 1427). While these issues can and should be addressed at a structural level, it will take time and resources. In the meantime, underprivileged individuals will continue to develop heart failure and lack the resources to properly manage the disease. Ideally, the healthcare system will adapt to improve prevention of heart failure development. Even if that does occur, history has shown the communities with the greatest need will likely experience a delayed benefit compared to more affluent areas. While the recent improvements in heart failure treatments are remarkable, it remains a disease in which social factors have an outsized impact on trajectory and outcome. Providers have an ethical obligation to meet each person where they are in their illness journey and provide them with the individualized education and support needed to improve their health. Early involvement of palliative care for underserved, minority heart failure patients will help to ensure each unique

illness journey is comprehensively understood, while falling in line with the urban bioethical principles of agency, social justice, and solidarity.

CHAPTER 3: PALLIATIVE CARE AND HEART FAILURE

The central tenets of palliative care services revolve around fostering communication for goals of care discussions, shared decision making, and caregiver support (Ferrell et al. 2018, 1684-5). These are skills regularly used by all types of doctors when interacting with patients. However, the tumultuous nature of heart failure requires significant cognitive demand from both a medical and social standpoint. A physician treating a patient hospitalized for a heart failure exacerbation with multiple comorbidities must first ensure the patient remains stable from a medical standpoint. While the provider may be perfectly capable of addressing the social factors contributing to the patient's presentation, the demands of patient care and administrative tasks may relegate those important discussions to the end of the hospitalization or a future outpatient visit. Involving the palliative care team early in the disease course allows the primary team to devote more attention to medical optimization, while the palliative team can implement its skills and knowledge to work towards social optimization. The World Health Organization recognizes access to palliative care for all who need it as an essential criterion for Universal Health Coverage (Sobanski et al. 2020, 13). Recent studies have attempted to determine which heart failure patient populations would most benefit from palliative care and explore whether all heart failure patients need palliative care support (Rogers et al. 2017, 331-340; O'Donnell et al. 2018, 516-519; Bakitas et al. 2020, 1203-1211). But heart failure patients from disenfranchised communities absolutely need palliative care to ensure they have the best shot at understanding their disease, managing their symptoms, and getting proper access to supportive resources. In a patient population

with such complex medical and social needs, this is too big of a task for one physician to handle alone.

The American Heart Association recommends considering a referral to a palliative care team for assistance with difficult decision making, symptom management in advanced disease, and caregiver support even as the patient continues to receive disease-modifying therapy (Allen et al. 2012, 1934). Several reviews recommend integration of palliative care for all patients with advanced heart failure (1937). While I agree with these recommendations, I believe they should be expanded to integrate palliative care early in the disease course for patients from underserved communities. Providers have an ethical responsibility to ensure individuals with limited access to healthcare, poor health literacy, and low socioeconomic status have appropriate resources to understand and manage their disease. For example, low health literacy is associated with poor self-care and increased mortality in older adults with chronic illnesses, like heart failure (1943). Additionally, much of the public does not view heart failure as a fatal disease (Janssen et al. 2019, 378-9). Someone with low health literacy will have an even harder time grasping the nature of heart failure and all that is required to manage it. Through no fault of his or her own, this person has limited agency to make an informed decision without extra support resources. Palliative care is already underused in minority populations, which is a driver of disparities at end of life (Warraich, Hernandez, Allen 2017, 1280). Including palliative care will allow the team to fully assess the individual's level of understanding by focusing on communication, goals of care discussions, and shared decision-making. This will enhance personalized care for individuals who need it most and strengthen solidarity between the patient and the primary provider.

It is well documented that heart failure patients have high symptom burden at end of life (Mosterd, Hoes 2007, 1139). This impacts not only the patient, but the caregiver as well. Warraich et al. notes that caregivers provide anywhere between six-71 hours of care per week for an average of four years. Caregivers also commonly lack an understanding of managing heart failure and feel unprepared to manage emergencies (2017, 1281). This substantial commitment takes a physical, emotional, and financial toll on the assisting individual, which is often a loved one of the patient (Kang, Lee, Nolan 2011, 391-392). For individuals with advanced heart failure in particular, caregivers are invaluable in the daily management of patient care for tasks such as administering medications, preparing meals, and assisting with transport. Buck et al. observed that strong social support leads to increased medication adherence, decreased hospital admission rates, and dietary compliance (2015, 80). It is understood that patients rely on caregivers substantially, but who can the caregivers rely on? Managing heart failure is a team effort and caregivers are the ones who are most often responding to the immediate needs of the patient. Palliative care plays a crucial role in assessing the illness understanding of both patient and caregiver. The specialty is also specifically trained to assess caregiver wellbeing. Cardiologists can and should involve caregivers in regular appointments and assessments. However, given the unpredictable nature of the disease, introducing palliative care early in the disease course strengthens solidarity between patient, caregiver, and provider. Though the primary objective will be properly caring for the patient, early introduction between the palliative team and the caregiver will allow more time to establish a relationship, develop rapport, and identify caregiver needs throughout the disease course. As the importance of wellness spreads throughout the medical community in the wake of

the pandemic, it is important to be mindful of how the wellness of caregivers impacts the care the heart failure patients receive. In underprivileged communities, mental health support services may be lacking (Alang 2019, 346-349). A palliative specialist will know how to connect individuals with the proper resources they require to ensure they are able to care for themselves, which will ultimately benefit the heart failure patient as well.

While the direct effects of heart failure manifest as physical symptoms, such as breathlessness and pain, mental health is severely impacted, as evidenced by estimations that 13-77% of heart failure patients suffer from depression (Allen 2012, 1943).

Depression is a negative prognostic indicator for this patient population, which leads to poor self-care, decreased medication adherence, increased smoking, and decreased activity (Sobanski et al. 2020, 18). In fact, Sobanski et al. recommends all heart failure patients be screened for depression (18). It is not feasible to expect cardiologists to perform depression screenings for all heart failure patients, both for lack of time and training in mental health care. A referral to a mental health provider would be an adequate step for individuals who are able to navigate the healthcare system. But in disadvantaged communities with poor access to mental health services, a referral is likely a dead end. Palliative care is specifically trained in assessing the psychosocial needs of patients and has the social work capacity to connect patients with the proper resources to access mental health services. Cardiologists have expertise in prescribing optimal guideline-directed medical therapy to alleviate physical symptoms. However, if depression is unassessed or unaddressed, medication adherence is likely to suffer, severely limiting the usefulness of the medication regimen despite the provider's best intentions. A multi-disciplinary team effort is the most effective way to ensure a patient's

physical and mental symptoms are properly assessed, addressed, and managed, especially when facing numerous social and structural barriers.

Advanced care planning is paramount to ensuring patients, providers, and family members are on the same page when it comes to disease management at that exact moment, but more importantly, in the future. As symptoms progress with heart failure, exacerbations become unpredictable in timing and severity. In 2013, only 14.3% of heart failure patients at one medical center had an advanced directive (Warraich, Hernandez, Allen 2017, 1281). Some advocate for a yearly heart failure review with the provider (Allen et al. 2012, 1929). This should be the bare minimum interval, considering another study found 19% of patients with advanced heart failure changed their preferences for resuscitation within two months (Krumholz et al. 1998, 650). This demonstrates the necessity of frequent communication due to the evolving nature of heart failure and each patient's change in goals, values, and preferences as his or her experience with illness changes. Another study examining a population of advanced heart failure patients with an ICD and at high risk of mortality found that while 78% had prognostic awareness, only 26% had had a goals of care discussion with their doctor (Gelfman et al. 2020, 328). This is an astonishing statistic given that this patient population is incredibly sick and close to the end-stage of illness. Of note, the authors remarked that future research is needed to examine how sociodemographic characteristics may affect prevalence of prognostic awareness and goals of care discussions (331). Considering the many missed opportunities to discuss personal goals with the population of advanced heart failure patients in this study, goals of care discussions might be occurring less among populations with low socioeconomic status. Clearly, there is much room for improvement

when it comes to eliciting goals of care for heart failure patients. This underscores the need to get palliative care involved early, particularly for underserved communities, because their primary job is to establish these personal preferences. It is a disservice to heart failure patients from disadvantaged communities who have had inadequate access to the healthcare system overtime, which has likely contributed to their disease, to hold off on connecting them with a specialty that can evaluate them as a whole individual. These patients deserve a multi-disciplinary team that can devote full attention to medical and social needs to guide them and their loved ones through their illness.

CHAPTER 4: NEEDS AND SYMPTOMS ASSESSMENTS SUPERSEDE END-OF-LIFE PROGNOSTICATION

Due to the turbulent nature of heart failure, end-of-life prognostication is and will likely remain incredibly difficult to predict on an individual basis. Many papers have discussed pivoting to a needs and symptoms assessment approach rather than trying to recognize end-of-life, especially when considering whether to integrate palliative care (Sobanski et al. 2020,15). There are a couple validated assessments to identify heart failure patients who can benefit from palliative care (Ament et al. 2021, 50). One example is the Needs Assessment Tool: Progressive Disease-Heart Failure (NAT: PD-HF) (Waller et al. 2013, 912-921), which was developed to capture the patient's and caregiver's needs during one assessment administered by a healthcare professional. While the utility of using NAT: PD-HF in various medical settings is debated, the shortcomings regarding demographic and socioeconomic parameters, as well as objective assessment of social needs, are worth discussing. The study was conducted among inpatients and outpatients at the cardiology department of a metropolitan referral hospital in Sydney, Australia. Patient demographics and socioeconomic status were not identified or discussed, limiting the ability to assess the validity among underserved patients. Additionally, participants were approached by clinic staff to participate, and eligibility criteria included understanding English sufficiently to complete the questionnaire. Implicit biases could influence recruitment if participant inclusion is subjectively mediated by the clinic staff. Non-English speakers would also be excluded based on the inclusion criteria, which would eliminate representation from individuals who are disproportionately from underserved, minority communities.

One single category did not exhibit significance in NAT: PD-HF when compared to a patient-completed needs assessment: that of social needs. The authors note this section was multifactorial in assessing health, social, and cultural beliefs, which may have contributed to a lack of specificity in assessment. It is well established that psychosocial support is crucial to effectively managing heart failure. The lack of significance in assessing social needs is a weakness when using the NAT: PD-HF tool. This underlines the importance of palliative care involvement. Whatever deficiencies are present in social needs assessment would be made up for by the expertise of the palliative care team. While the tool should continue to be developed to improve social needs assessment, the use of palliative care is crucial to filling in the gaps for all heart failure patients, let alone those who are unable to adequately access or navigate the healthcare system.

Another study commonly referenced in the literature is by Kane et al., which used the Integrated Palliative Care Outcome Scale (IPOS) (2018, 143-150). IPOS is a patient-reported outcome measure used to identify unrecognized physical, psychosocial, and spiritual needs, as well as improve communication. Patients and nurses involved in the study reported this patient-centered approach did identify unmet needs and topics that worried them most.

The demographics of the study participants are worth examining. The patients involved were selected for age, sex, New York Heart Association classification, and heart failure type. Eighteen patients were interviewed, eleven of whom were male. While socioeconomic status was not explicitly reported, participants were asked about their education level. Over 50% had completed or had some secondary education and 31% had

primary education only. The small sample size and limited demographic information make it difficult to generalize the study results to low-income, minority communities.

Despite the limitations in generalizability, the IPOS study does address broader themes regarding the attitudes towards social support for patients and providers.

Participating nurses noted psychosocial concerns were frequently only considered at end-of-life, but the IPOS study allowed these needs to be met earlier. Additionally, twelve of the patients discussed anxiety experienced by them and their caregivers. Perhaps the most important revelation was nurses openly admitted they hoped patients would not score a section about becoming newly distressed because the nurses were unsure how to determine patients' needs.

Even though IPOS helps identify unmet patient needs, it is not widely adopted among practices. Without a standard needs assessment, many patients' needs, particularly psychosocial, will remain unaddressed for too long. The fact that 12 of the 18 patients discussed their illness-related anxiety is telling of just how much psychological distress goes unaddressed, despite being at the forefront of patient's minds. Most concerning for patient's overall well-being is how uncomfortable nurses working in a heart failure clinic felt about addressing psychosocial needs of patients if they arose during the interview. Those discussions certainly are not easy, but they are incredibly important for the patient's holistic health. The themes arising from this study point to the importance of early involvement of palliative care. Until standardized communication tools become more widespread in heart failure practices, many members of the healthcare team will likely feel inadequately prepared to address psychosocial needs as they arise. Palliative care is specifically trained to have these discussions. Getting them on board early will

help ensure the entire spectrum of patient needs is addressed, while relieving stress from the primary team that wants to help the patient but may not know how best to do so.

It is unknown how well the current validated needs and symptoms assessments accurately capture the experiences of minority and disadvantaged patients. Future studies are needed that specifically interact with these patient populations to determine how well the tools identify their needs. Until then, it is prudent to work under the assumption that many needs and symptoms are not adequately addressed. It is unrealistic to assume that communities with such a high prevalence of risk factors, such as diabetes and hypertension, would have a firm handle on heart failure management. Therefore, it is only just that they are provided with extra resources to ensure they are getting the best care possible. An optimal approach is to involve palliative care early in the course of the disease.

Though the physical and psychosocial needs of heart failure patients are complex, not all patients with palliative care needs require a palliative care specialist. Certain clinical sites or settings, such as an independent outpatient practice, may not have access to a palliative care team. In these situations, it is important for heart failure providers to be cognizant of regularly assessing and addressing the social needs of patients. As discussed with the IPOS study, it is important in these situations that all members of the care team have adequate training to assess and address psychosocial needs of patients and caregivers. However, large tertiary care centers, especially safety-net hospitals and those caring for predominantly underserved populations, likely have sufficient palliative care services. Jansen et al. argues that optimal timing for a palliative care needs assessment is during an admission due to deterioration (2019, 379). Sobanski et al. is in favor of

holding advanced care planning discussions at transition points of the disease course, such as a hospital admission, increased symptom burden, or declining health despite optimal guideline-directed medical therapy (2020, 19). Each provider will have an opinion as to when a palliative consult is appropriate. When it comes to disenfranchised heart failure patients with poor access to healthcare, a hospital admission for an exacerbation should be the lowest threshold for a palliative consult. At a minimum, the consult will establish a new relationship between the patient and another care team uniquely trained to identify social needs, as well as goals, values, and preferences. If the patient is already known to the palliative team, a consult during an admission will improve solidarity between the patient, the heart failure service, and the palliative service as all work in tandem to identify mechanisms to improve the patient's health status. Involving the palliative care team strengthens social justice for heart failure patients from underserved communities who have not had adequate education or access to resources to improve their health. The additional social and emotional support provided by palliative care is a vital resource for assisting these patients in overcoming the contextual and structural inequities they have faced in their illness experience.

CHAPTER 5: BARRIERS TO PATIENTS RECEIVING PALLIATIVE CARE

As previously mentioned, the fluctuating course of heart failure and variability in patient presentation makes end-of-life prognostication extremely difficult. In a world where individuals are used to having an answer to a question with a few clicks of a keyboard, an unknown prognosis places undue stress on patients, family, and caregivers. Like many types of cancer, heart failure is an incurable disease with decreased life expectancy. However, cancer has a robust association with palliative care services, whereas heart failure does not. For individuals with advanced cancer, goals of care discussions are associated with improved quality of life, decreased healthcare costs, decreased family burden, improved family satisfaction, and better bereavement outcomes (Gelfman et al. 2020, 327). There is no reason to suspect heart failure patients and their families would not experience similar benefits from these discussions. In fact, it has been shown that when doctors have discussions about goals and values with heart failure patients, families have better outcomes in terms of how they cope with loss and their own psychological outcomes (Allen et al. 2012, 1939). However, individuals with cancer and heart failure approach their disease with a different mindset. Due to decades of public health outreach to increase cancer awareness, most people with a new cancer diagnosis likely understand the severity of the disease and are open to the vast array of services offered, including palliative care. Heart failure has not benefited from the same type of exposure, hindering the public's knowledge of the disease and its characteristics. Janssen et al. identified the fact that patients do not see heart failure as a life-limiting disease as a barrier to them receiving palliative care services (2019, 378-79).

If the public has a poor understanding of heart failure, this knowledge deficit is likely exacerbated in communities with poor access to healthcare resources. Using the COVID-19 pandemic as an example, many states reported the zip codes most impacted by the virus were also the poorest (Raine et al. 2020, 9) and tended to consist of racial minorities. A multitude of factors contributing to these disparities, such as decreased access to education, employment, stable housing, reliable internet, and healthy food, were brought to light by the pandemic. The negative health effects of these longstanding disparities are not limited to COVID-19. These communities have higher incidences of diabetes, hypertension, and obesity (Raine et al. 2020, 2), which are all risk factors for heart failure. Clearly, the social and structural determinants of health that negatively impact poor and minority communities are numerous and require multifactorial, interdisciplinary approaches to alleviating them. When it comes to heart failure, several studies argue that targeting contributing factors that have roots much earlier in life are needed to address disparities that cause disabilities later in life between whites and Blacks (Freedman, Spillman 2016, 7). The most ideal way to manage heart failure in disadvantaged communities would be to mitigate the risk factors and inequalities that lead to it. While healthcare providers should play a role in increasing awareness of these disparities, this thesis focuses on measures to assist heart failure patients from underserved communities in managing their disease once they are diagnosed. One such measure is utilizing the skills and resources of palliative care.

There are a multitude of reasons why heart failure patients across the demographic spectrum do not receive palliative care services. One stark example is the difficulty physicians have in accurately assessing survival for patients with advanced

cardiovascular disease and deciding when to engage in a palliative care discussion (Warraich, Hernandez, Allen 2017, 1283-4). Due to the multifactorial nature of cardiovascular disease, particularly heart failure, it is unfair to patients and providers to expect physicians to offer an accurate prognosis for the disease. However, this prognostic difficulty can result in delays in receiving palliative care services. If there are any doubts about the stability of a patient's health status, there is an ethical obligation to ensure the individual has a robust understanding of his or her condition, no matter how ambiguous. Involving palliative care falls in line with the principle of beneficence and strengthens solidarity in the patient-provider relationship. Although palliative care can have a negative connotation, if the provider explains the role of palliative care is to provide additional support and it is being done in the best interest of the patient's health, he or she is likely to find comfort and reassurance.

Even if physicians were able to offer accurate prognoses for those approaching end-stage heart failure, a sizable portion of the population would be unlikely to accept the services offered by the palliative realm. There is an increased reluctance for palliative care in minorities, which is attributable to poor health literacy (Warraich, Hernandez, Allen 2017, 1284). Black individuals are more likely to prefer aggressive treatment in the event of terminal illness and have a lower use of Do Not Resuscitate orders compared to whites (Schonwetter et al. 2008, 1144). In underserved, minority communities, medical distrust has compounded the issue of providing palliative resources to the individuals who tend to need more support. In the context of historical mistreatment of minority populations in medical settings, it is understandable why these individuals would pursue all available options to prolong life, even if quality of life is sacrificed (Schonwetter et al.

2008, 1144). It is also easy to see why these communities would be wary of palliative services, considering most of the public believes it to be associated with the end of life. Those with poor health literacy also may quickly jump to a measure described as helping them to live longer, especially if they do not fully understand the trade-off in quality of life. Because the principle of social justice requires equitable access to opportunity (Reeves, Jones 2022, 501), it is not enough for providers to give the same general pitch to each patient who would benefit from palliative care. Patients from disadvantaged areas who are less likely to trust or understand the medical community require more in-depth explanation as to what palliative care is and how it would benefit the individual. While a generalized palliative care recommendation for all patients who need it provides an equal opportunity, a personalized discussion that accounts for everyone's social and structural context paves the way for an equitable opportunity. This also enforces the concept that a provider is working in solidarity with each patient to ensure he or she is making the best decisions to align with the individual's values. This falls in line with meeting each patient where he or she is in the illness journey.

One crucial resource that is scarce throughout all of medicine is time. Meaningful conversations regarding goals, values, and preferences are delicate matters that cannot be rushed. The medical aspects of heart failure are complex enough to exceed the allotted time for patient visits. Despite best efforts, topics such as advanced care planning are pushed aside in the face of time constraints. The American Heart Association acknowledges that a diverse inclusion of healthcare providers is needed to ensure the social needs of heart failure patients are met (Allen et al. 2012, 1945). It is not a failure on the part of the cardiology team to involve palliative care. Rather, it strengthens

solidarity by working in the best interest of the patient to involve a service whose primary objective could be to assess and tend to the psychosocial needs of the patient and caregiver. It also works towards ensuring social justice is achieved by providing individuals who need more social assessment and support access to members of the healthcare system who are specifically trained to assist with those elements.

CHAPTER 6: EDUCATION

Education is one of the central tenets to ensuring heart failure patients have the agency to make informed decisions about managing their health. This involves a two-pronged approach: 1) increasing knowledge about the heart failure disease process, and 2) explaining what palliative care is and the services it provides. While there are tools to improve education (Allen et al. 2012, 1940; Butler et al. 2014, 410), there is no substitute for the impact a face-to-face conversation between patient and provider has on a patient's knowledge and overall outlook. Whether these conversations are initiated by heart failure specialists, palliative care specialists, or both, it is invaluable to patient care and enforces a sense of solidarity. Given the lack of public knowledge about heart failure mortality, providers should not generally assume each patient adequately understands the scope of the disease. Additionally, introducing the concept of palliative care early in the disease course helps to normalize the specialty and gives patients sufficient time to explore the additional support options the field offers.

While it is crucial that patients are provided with educational opportunities to learn about heart failure, it is unrealistic to expect all providers to individually develop the skills to assess understanding and address deficiencies, especially when it comes to palliative care topics. Studies have shown healthcare professionals themselves require tools that increase awareness, understanding, and knowledge concerning palliative care needs (Ament et al. 2021, 54). Other studies have shown that specific communication skills training enables providers to help patients understand their illness and elicit goals and values as the patient gets sicker (Gelfman et al. 2020, 331). While heart failure providers should receive special training to maximize the ability to understand patients'

goals and values to provide holistic care, doctors will still be strapped for time during routine visits, limiting the ability to fully utilize these skills. Additionally, not everyone will feel comfortable initiating these conversations, especially if the patient has been relatively asymptomatic for some time. Involving palliative care ensures these conversations are happening in tandem with appropriate medical care and that all needs, especially psychosocial, are being met in real time.

Until there is widespread adoption of tools and techniques for heart failure providers to address palliative needs, providers are ethically obligated to involve the palliative care experts early and often when available, especially for the most vulnerable patient populations.

CHAPTER 7: FUTURE DIRECTIONS

The tumultuous nature of heart failure and its unique impact on each individual patient will likely prohibit improvement in prognostication for the foreseeable future. Due to the impressive advancements in heart failure treatment, more people will be living with heart failure than ever before. Taking steps to reduce risk factors for heart failure, such as hypertension and diabetes, are ideal. However, these are large undertakings that need time and tremendous resources. Underserved, minority communities experience disproportionate levels of risk factors due to social and structural barriers of health. As such, they have disproportionately worse outcomes in heart failure management. Though there are validated needs-based heart failure assessments, none have been universally adopted in clinics. If these tools have not been widely implemented in well-funded healthcare settings, the probability of them being routinely used in resource-poor settings is low. Additionally, most of the study populations are not representative of low-income, minority communities who experience the most hardship in accessing the healthcare system. In truth, a tool does not yet exist that is specifically designed to identify the unmet needs of heart failure patients from disadvantaged backgrounds.

Because heart failure patients and their caregivers in underserved communities have so many barriers to effectively managing their condition, heart failure providers must offer as many resources as possible to set these patients up for success. Palliative care can play an outsized role in a multi-disciplinary approach to caring for the whole individual. There is a growing consensus that palliative care should play an integral role in the management of severe heart failure. There are still questions as to when the most opportune time is to bring in the palliative care team. Validated studies have been

published utilizing questionnaires that show promise in evaluating psychosocial needs of patients and caregivers. However, there is a lack of evidence that specifically examines how palliative care involvement and the questionnaires benefit underserved communities. Until these gaps are sufficiently addressed, it is imperative that these vulnerable patient populations receive as much support as possible to manage heart failure and receive multi-disciplinary care. Early involvement of palliative care for heart failure patients from underserved communities falls in line with the urban bioethical principles of agency, social justice, and solidarity.

Because agency depends on personal context and one's ability to see a complete range of options (Reeves, Jones 2022, 499-501), individuals with poor health literacy may have difficulty understanding the full implications of their medical decisions, especially serious ones, such as initiating Left Ventricular Assist Device treatment. Or an individual who has had unpleasant personal or family experiences within the healthcare system may not pursue treatment options that seem completely routine and reasonable to the provider. The palliative team is uniquely trained to gain an understanding of a patient's personal context to help the patient and primary team come to a mutual decision via shared decision-making.

Social justice requires equitable access to opportunity (Reeves, Jones 2022, 501-503). Heart failure requires a great deal of resources and effort to properly manage. Adhering to multiple medications, adjusting one's diet, increasing exercise, and traveling to appointments are just a few examples of new routines that must be developed. These are all major lifestyle changes happening very suddenly, which would be stressful to handle even for someone with the resources to do so and the wherewithal to navigate the

healthcare system. As heart failure progresses, these stressors are multiplied as they are adopted by the caregivers recruited to assist the patient in activities of daily living.

Equitable access involves providing extra resources to those in need so all patients can reach the same state of health. Underprivileged patients face numerous social and structural barriers through every step of their illness journey. Palliative care is a vital and underutilized resource that can undoubtedly boost the patient's chances of adequately managing his or her disease because the specialty can skillfully assess the patient's medical, social, and spiritual needs, while also overcoming structural barriers with the help of social workers.

Solidarity is a principle that is followed across all medical specialties (Reeves, Jones 2022, 503-504). A patient entrusts his or her well-being to the physician and the physician pledges to guide the individual towards a healthy outcome to the best of his or her ability. Asking for help along the way is common and expected, such as when a hospitalist consults a gastroenterologist when a patient is suspected of having an intestinal bleed. Due to the stigma of palliative care and a general misunderstanding of the resources it provides, asking for palliative assistance when a patient is not imminently dying is not nearly as common. Recruiting palliative care does not mean the physician has failed in managing the patient's condition, especially with a disease as complex as heart failure. Rather, it is a clear signal that the provider is pursuing every available avenue to ensure the patient is receiving holistic care to maximize the chances of a healthier life. Once the patient understands the palliative care team offers another level of enhanced support, the bond of solidarity will likely be strengthened as the patient gains a

greater sense of trust and comfort knowing the provider is striving to ensure all the patient's needs are identified and addressed in a timely fashion.

Heart failure management is challenging because social background and lifestyle choices play a significant role. Heart failure patients from disadvantaged, minority communities have a litany of social and structural barriers stacked against them as they strive to manage their disease and pursue a healthier life. Involving palliative care early for this patient population fulfills the urban bioethical principles of agency, social justice, and solidarity and ideally will improve physical and mental outcomes by tailoring treatment to each individual patient's unique illness experience.

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