Review Article on Palliative Care and Surgery

Surgical palliative care disparities

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Abstract: Surgical palliative care is an interdisciplinary treatment modality that aims to decrease suffering and improve the quality of life of seriously ill surgical patients. Although surgical palliative care is increasingly being found to positively impact patient quality of life, disparities in surgical palliative care remain poorly defined. While the field of medical palliative care has demonstrated certain racial/ethnic, socioeconomic, and geographic groups are at higher risks for receiving worse palliative care, there is no analogous consensus in the field of surgical palliative care. This is largely secondary to a paucity of research focus in this field. Given that the aforementioned disparities experienced by minoritized patient populations has led to significant morbidity, it is important to understand and call attention to disparities existing within the field of surgical palliative care as well. To advance the knowledge of current healthcare shortcomings and progress towards equitable surgical palliative care, this paper reviews the current state of surgical palliative care disparities evidence, details gaps in knowledge, and highlights priorities for future surgical palliative care research. The articles identified in this review noted disparate surgical palliative care access and outcomes across various racial/ethnic groups, age ranges, socioeconomic classes, hospital populations, and regions. However, evidence scarcity necessitates more robust research be performed to adequately identify at risk groups and understand the factors supporting disparity development.

Keywords: Healthcare disparities; surgery; palliative

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Introduction

Healthcare disparities for certain priority population groups, such as racial/ethnic minorities and rural populations, have been widely documented in both medical and surgical fields (1-5). Worse access, quality of care, and outcomes all contribute to a significantly increased health burden in these groups (6,7). Unsurprisingly, previous studies have also established that minority groups experience worse care in palliative care domains such as symptom management, quality of life (QOL) improvement, advanced care planning, and alignment of doctor and patient healthcare goals (8,9). Unfortunately, less is known about disparities in the subset of palliative care dealing with surgical patients experiencing a significantly decreased QOL, commonly referred to as surgical palliative care. Disparities in surgical palliative care specifically may be clinically magnified by the fact that surgical patients often carry higher burdens of disease, shortened survival, and a significantly decreased QOL compared to their medical counterparts (10). To emphasize the importance of the issue, the NIH, and American College of Surgeons in 2016 designated improving patient centeredness and palliative care as one of the top 5 surgical disparities research priorities (11).

Currently, surgical palliative care is an understudied field with a patient base experiencing significant illness. To promote understanding of what disparities exist, where they exist, and how they might impact different populations, this paper aimed to review and summarize the current literature on disparities in surgical palliative care.

Definitions

To understand the scope of the surgical palliative care field, it is important to highlight a few key definitions. Surgical palliative care is an interdisciplinary treatment modality that aims to improve the QOL of patients suffering from serious surgical illness—i.e., those who are likely to die from their illness or be significantly hindered by it (10,12). Importantly, surgical palliative care is an approach to care, not just the act of surgery itself. Palliative surgery is just one tool in the surgical palliative care toolkit, and therapies besides surgery, such as emotional support and pain management, can be used to improve the QOL for surgical patients and their families. An 11-item criterion was curated and validated by Lee *et al.* to define specific serious illness conditions and included ailments such as end-stage renal disease and an ASA Risk Score class of IV or V (10). In short, surgical patients with serious illness are the unique population of study, and the changing needs of this population based on different factors, such as race, age, or geography, are important to understand.

Exploring access disparities in fields related to surgical palliative care

Before exploring the disparities specifically pertaining to surgical palliative care, it is of use to highlight the widely established disparities in the field of palliative care as a whole. Multiple disparities at different levels of healthcare play a role in decreasing access to palliative care. These disparities have been identified at individual patient-physician and hospital/systemic levels.

At the individual patient-physician level, race, age, physician biases including reluctance to refer, and communication barriers have all been shown to significantly decrease palliative care access. With regards to racial differences, Black and Hispanic patients have been shown to receive lower rates of palliative care compared to White patients (13-15). Another study found that Black patients tend to be sicker before receiving palliative care, and are less likely to leave from a hospital alive after having received palliative care (16). Factors that play a role in generating this racial disparity include differences in utilization and social factors. More specifically treatment preferences, cultural preferences for end of life care, and knowledge differences have been suggested to decrease racial utilization of hospice care services (17). Other social determinants that generate disparities in palliative care include financial/insurance barriers and misconceptions/lack of information about palliative care (18). Taken together, this supports the notion that race plays a complex, multidimensional role in the reception of palliative healthcare.

Several communication barriers, mediated by patient or physician preferences or linguistic differences, have also been shown to significantly influence palliative care access. From the patient perspective, patients reported a desired to focus on life-preserving options rather than death-related domains as well as a lack of understanding of preferred care for serious illness as reasons for avoiding initiating palliative care conversations (19). When patients or physicians do initiate palliative care conversations, barriers in language interpretations can result in patient misunderstanding of their disease process along with worse QOL if patients' goals of care do not align with their physicians' actions (20,21). For other patients, difficulty understanding medical terminology or palliative care options decrease access. Within the senior patient population specifically, it has been shown that inability to accurately hear health-related conversations can lead to decreased comprehension (22). Taken together these factors produce a system in which palliative care might not be prioritized.

At the hospital level, there is evidence that disparities persist outside of factors directly attributable to one patient or physician. When Faigle *et al.* explored system-level factors contributing to racial disparities in palliative care use after stroke, it was found that White and Black patients at predominantly minority-serving hospitals were less likely to receive palliative care compared to White and Black patients at predominantly non-minority serving hospitals (23). Subsequent studies have continued to highlight that patients at predominantly minority-serving hospitals are less likely to receive palliative care, regardless of race (24).

Finally, geographic limitations play a significant systemic role in limiting palliative care access. Ideally palliative care is administered as an interdisciplinary approach that addresses patient and family physical, psychosocial, and spiritual concerns. Rural medicine in particular commonly falls short of this gold standard because of inadequate primary care physician education and training, inadequate preparation for symptom control and emotional counseling, and primary care physician difficulty in accessing specialist services when they are needed (25,26). Geographic distance has also been noted as creating time constraints that decreases administration of rural palliative care and decreases the professional development required to learn and maintain an understanding of the use of palliative care (25,26). Notably, the 2019 State-By-State Report Card on Access to Palliative Care in Our Nation's Hospitals reported that 90% of hospitals with palliative care are in urban areas. Further, only 17% of rural hospitals with 50 or more beds reported having palliative care programs. In short, where you live matters in terms of access to palliative care (27).

Although palliative care in medical and surgical populations is related in mission, it would be shortsighted to immediately begin investing resources to increase surgical palliative care access without acknowledging the specific barriers to access in surgical populations. While we can learn from the disparities experienced above, it is important to note how the two populations differ significantly. Surgical patients not only suffer from serious illness in need of direct intervention, they also deal with the added pressures of understanding and making quick care decisions during an accelerated perioperative time frame (28). For older adults, treatment decisions typically become more complex with advancing age. Patients must decide if they prefer aggressive treatments that negatively impact their QOL in the short term for a potential increase in lifespan versus QOL-conserving treatments without expected survival benefit (29). These considerations are especially difficult and sensitive to personal patient values due to the scarcity of data comparing long term QOL and function maintenance across operative and nonoperative treatments (28). The shortened time frame, added considerations that come with perioperative advance care planning, and causal disease differences necessitate understanding potential disparities in care from a surgical palliative care lens specifically.

Exploring the disparities in surgical palliative care access

Barriers to accessing care are integral drivers of worse quality of care overall and specific disparities. Mediators to health care access can range from individual physician decisions, to cultural preferences, to structural factors. Characterizing known disparities in surgical palliative care access among different populations is essential to providing quality healthcare for all.

Evidence for disparities in surgical palliative care access

Multiple studies have consistently shown that across all populations, surgical patients are less likely to receive palliative care compared to medical patients (30-32). Lack of education, physician biases, and a "fix it" culture have been described as fundamental reasons for this discrepancy. One reason for the reluctance to refer is a lack of education. Surgeons report a lack of training to engage in palliative discussions (33). With regards to biases, some physicians' views that palliative care is most useful at the end of life, coupled with views that early use of palliative care is a sign of giving up contributes to the variable and typically late usage of palliative care (34-38). There is a strong culture in surgery to fix an established problem and to save lives. This has led to palliative care being seen as both secondary to and a failure of the "fix it" primary mission (39). Mosenthal *et al.* noted that external factors, such as the use of surgical morbidity and mortality as healthcare quality indicators and the public reporting of this data further reinforce the sense of personal failure surgeons feel when poor outcomes are experienced (39). Such external factors further delay prioritization of palliative goals of card that don't aim treat a patient's condition rather than improve their QOL (39).

Novel research has begun to highlight specific surgical patient populations at risk for decreased palliative care access, defining "priority populations" for surgical palliative care. A review of the national inpatient sample by Heller *et al.* found that predictors for surgical palliative care administration are partially similar to those described for the palliative care field as a whole (40). Patients at a higher risk for death such as increased age and comorbidities, receiving care in an academic not for profit, large hospital, and living in a region outside of the northeast all predicted an increased likelihood of receiving surgical palliative care (40). It is notable that investigators found the northeast a negative predictor of surgical palliative care reception since the center to advance palliative reports patients in the northeast have access to significantly more hospital palliative care programs (27). The researchers suggested geographic differences and biases in goals of care, decisions making, and expectations of surgical outcomes among surgeons or patients were potential reasons for this disparity.

Unfortunately, few studies have looked at racial, ethnic, and socioeconomic disparities in palliative care delivery to surgical populations specifically. Although surgical palliative care access disparities have been described, there is still much to learn about who has access to palliative care and how it is different among different populations. For racial/ethnic minorities, there is currently no consensus on the influence race plays on surgical palliative care access. One study determined that African American and Hispanic patients are less likely to receive palliative interventions while waiting for liver transplantation (41). Regarding socioeconomic status, another study found that patients with lower SES were less likely to be referred for palliative colorectal stenting for malignant obstructions (42).

Evidence gaps in understanding surgical palliative care access disparities

The major gaps of knowledge regarding disparities in surgical palliative care access surround effective communication and decision making techniques and efficient palliative healthcare delivery (28). With regards to communication, an expert consensus conference hosted by the National Institutes of Health and National Palliative Care Research Center highlighted the need for better communication techniques to help surgeons guide advanced care planning conversations, complete conversations detailing patient's desired outcomes from palliative procedures, and provide reasonable prognostic predictions in times of uncertainty (28). Without the knowledge of how to guide these conversations, surgeons must rely on assumptions of patient preferences and feelings of what seems right to disclose.

With regards to palliative healthcare delivery, the group noted that efficient scalable models and screening tools must be made to allow for the seamless integration of palliative care into surgical care (28). Whether or not better delivery of palliative care will impact barriers to palliative care access such as patient knowledge of resources, resource limitation, of palliative care value misunderstandings has yet to be determined. Future research and solutions should be designed in such a way as to decrease the wholistic individual, hospital level, and systemic barriers while concurrently prioritizing disparities studies research.

What's next in surgical palliative care access

Moving forward, the field of surgical palliative care must expand its access to all patients while also investing in specific disparity identification, research, and solution discovery, the three domains of disparities research (43). The relationship is mutually beneficial as increased access will drive any disparity findings and disparity findings will inform equitable surgical palliative care research design. Previous research has already defined potentially effective tools to increase palliative care access at an individual and hospital level, including the palliative care triangle method and palliative care triggers. The palliative care triangle is a decision making model that includes surgeons, patients, and their families in conversations to help guide individual decisions regarding palliative care (44). The model helps care teams and patients make decisions by taking patients' "complaints, values, and emotional support" into account versus surgical and medical treatment options (44). By helping to select patients with the most to gain from palliative operations, the method is cited as a means to help overcome the lack of formal training surgeons have in palliative care in a cost efficient and consistent manner (44,45). As a second solution to increase access, multiple studies have successfully implemented a system of triggers that clearly characterize opportunities to iterate palliative care into a surgical patient's healthcare (46-48). In addition to increasing the application of the palliative triangle and triggers, surgeons should be supported further with education regarding the utility of palliative care, how to provide primary palliative care, and the necessity to treat patients individually to help avoid stereotyping palliative care as a "last option". Lastly, future studies must also determine potential systemic level access barriers solutions such as investing money to increase palliative care programs within states and regions with few palliative care containing hospitals. As access to palliative medicine is increased, it must be kept in mind that these barriers could affect priority populations differentially. It will become increasingly important to sub stratify research by commonly marginalized priority populations to determine if these increases in access are being shared equally.

Disparities in surgical palliative care outcomes

Studies have shown early integration of surgical palliative care into disease management improves symptom management, advanced care planning, and coordination of care while reducing hospital length of stay, odds of readmissions, and healthcare cost (49-54). Although it is not currently possible to determine which surgical palliative interventions and outcomes are most effective due to study heterogeneity, it remains clear that surgical palliative care has a positive impact (30). As palliative interventions and outcomes are standardized, it is important to also detail any potential disparities in surgical palliative care outcomes among priority populations.

Evidence for disparities in surgical palliative care outcomes

Although there is no current consensus on whether certain

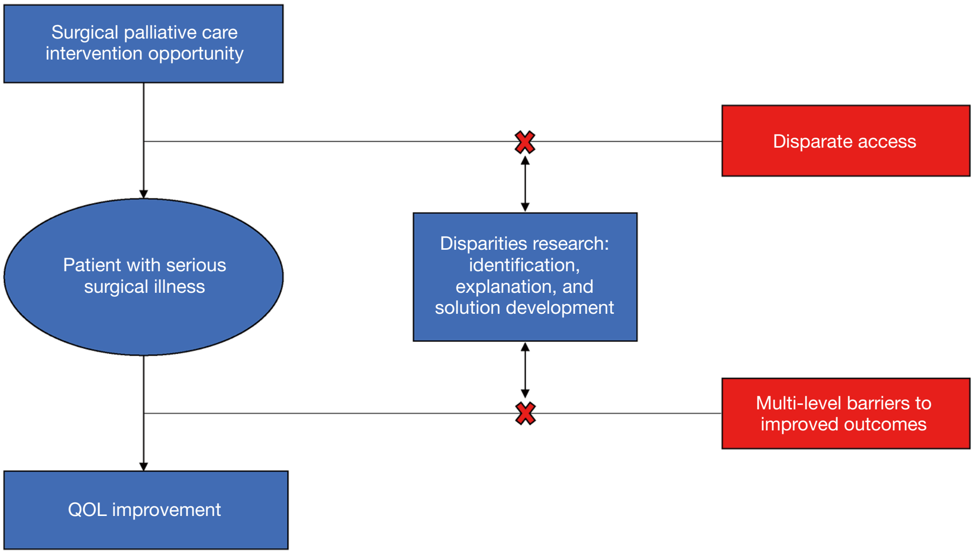

Figure 1 Targets for disparities research in surgical palliative care. QOL, quality of life.

priority populations experience worse surgical palliative care outcomes compared to non-priority populations, some research suggests differences exist at systemic and individual levels. At a systemic level, Hammad *et al.* found that treatment at a non-academic center was a negative predictor of survival when comparing palliative interventions on patients with hepatocellular carcinoma (55). At an individual level, the study found that advanced age and multiple comorbidities were negative predictors of survival following palliative intervention (55). Across racial/ethnic priority populations, studies have shown worse pain, communication, satisfaction, and advance care outcomes in the African American community, including surgical patient populations (56). Another study highlighting racial/disparities found that only 40.4% of Black families rated their lost ones' end of life care after high-risk surgery as excellent compared to 54% of White families (57). This theme that African American families are less satisfied with their care compared to White families has been well described in the literature (58,59). Although these emerging findings begin to point to populations with disparate surgical palliative care outcomes, it is important to appreciate the limitations of surgical palliative care research. For example, when comparing families' approval of their loved one's end of life care, it can be difficult to pinpoint the most important driving factors for the differential dissatisfaction. More specifically, it is not clear if differential treatment and a better experience was received during the last few weeks of care or if palliative care was different throughout the patient's disease course. Further, patient-level differences in palliative care expectations or awareness about treatment options could drive differential ratings. There are a multitude of nuances driving surgical palliative care outcomes and disparities research must be careful to account for these nuances. By appreciating these components driving disparities we can move past identification of potential underlying causes, and more efficiently detail solutions.

Evidence gaps and future directions for understanding surgical palliative care outcomes disparities

Much work still needs to be done to determine if significant disparities in surgical palliative care outcomes exist across different populations. Most of the current surgical palliative care research invests in understanding its proper indications, innovating new ways to increase accessibility, and defining what outcomes matter (30,60,61). Because of the extensive healthcare disparities experienced throughout other fields of medicine, it is also important to recognize how surgical palliative care advances might disparately affect various at-risk groups such as rural populations, racial/ethnic minorities, and older adults. Future actions should prioritize defining generalizable outcomes, performing multi-institutional high-quality studies, and investing in disparity research. The domains to invest in to move forward towards equitable surgical palliative care are summarized in *Figure 1*.

From 1994 to 2014, there were only 25 studies centered on palliative care interventions for surgical patients (30). This clearly denotes the need for more surgical palliative care research and highlight great opportunity for growth including opportunities to address disparities.

Conclusions

Emerging evidence in palliative care research suggests that disparate palliative care access and outcomes exist for certain surgical patient populations on the basis of race, age, socioeconomic status, and geographical region. However, more work needs to be done to better define these differences in surgical patient populations. Although disparities data is trending towards similar at-risk populations as seen in medical palliative care, it is not enough to extrapolate findings from the medical field to design solutions for surgical palliative care disparities. Future research must advance accessibility and outcomes measurement tools specific to surgical palliative care while considering the different populations that are affected within each study. As future research establishes more robust data, disparities can be clearly identified, understood, and addressed effectively. Future surgical palliative care disparity studies have a valuable task ahead of them with the potential to shape policy and clinical practice that aims to provide equitable QOL improving care to uniquely vulnerable health care populations.

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Footnote

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