



Political economy of hope as a cultural facet of biomedicalization: A qualitative examination of constraints to hospice utilization among U.S. end-stage cancer patients

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ABSTRACT

A growing body of social science literature is devoted to describing processes of biomedicalization. The issue of biomedicalization is especially relevant for individuals suffering from end-stage cancer and hoping that aggressive end-of-life interventions, which are riddled with uncertainty around quantity or quality of life, will produce a ‘cure’. To examine hospice underutilization among end-stage cancer patients, we apply the anthropological concept ‘political economy of hope,’ which describes how personal and collective ‘hope’ is associated with the political and economic structures that produce biomedicalization processes. Previous studies have examined hospice underutilization among end-stage cancer patients and have identified barriers stemming from patient and physician characteristics or health insurance reimbursement policies. Yet, these studies do not provide an organized synthesis of how barriers articulate, how they are part of the longitudinal decision-making process, or describe the sociocultural context surrounding hospice care enrollment decisions. This paper focuses on US-specific mechanisms and is based on qualitative, in-depth, interviews with physicians at an academic hospital (N = 24). We find that hospice underutilization results from a web of interconnected constraints surrounding end-stage cancer patients. Our research reveals how hospice care contradicts the political and economic structures associated with end-stage cancer care and illustrates how end-stage cancer patients are transformed into a form of biovalue, a fundamental commodity sustaining the political economy of hope.

Social scientists and others have developed a growing body of research theorizing biomedicalization, a term referring to an era of increasingly complex and multifaceted processes of medicalization made possible through technoscientific innovations and the (re)production of the human body (Clarke et al., 2003). The “medical industrial complex,” a key construct of biomedicalization theory, refers to the expansion of corporatization and commodification of health and health care that generates new spaces for biomedical intervention. Biomedical and pharmaceutical industries have fueled a proliferation of clinical trials, leading, in turn, to a growing portfolio of FDA-approved treatment options and rendering treatments that were once extraordinary to be part of a new normal in medical care (Kaufman, 2015). The increasing availability of biomedical interventions is reshaping patient expectations and norms by making it increasingly difficult to ascertain how much medical intervention is needed, wanted, or appropriate (Kaufman et al., 2004). The effects of biomedicalization are especially apparent in the case of end-of-life decision making, where stakes are high and biotechnological advances mean new treatments are continuously emerging. The challenges of decision making are especially

acute for individuals suffering from end-stage cancer, where aggressive interventions may be promising, but are riddled with uncertainty around increasing quantity or quality of life.

As biomedicalization of end-stage cancer patients increases, hospice services in the United States are concurrently expanding, both in terms of geographic availability and utilization rates. Hospice care is shown to effectively address a wide range of critical issues facing patients and their families at the end-of-life, including increased quality of life, dying with dignity, alleviating the burden placed on caregivers, higher patient and family satisfaction, and increased time of patient survival (A. J. Brown et al., 2014; Wright et al., 2016). Still, the allure of a ‘cure’ for cancer inspires hope in cancer patients and society that new biomedical interventions will produce benefits. As a result, ‘hope’ motivates many patients to forego the benefits of hospice care in order to continue with aggressive biomedical interventions towards the end-of-life (Wright and Katz, 2007). Understanding this paradox of hospice underutilization is an ongoing puzzle with a solution that has evaded scholars from many disciplines, who have conceived hospice barriers as a series of hurdles that patients must overcome. In this article, we use qualitative

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interviews with physicians treating end-stage patients with incurable cancer to examine biomedicalization of the end-stage cancer decision-making process within a US-specific context. Our findings reveal how end-stage patients are embedded within a complex web of structural forces, which influence patients' decisions to continue aggressive treatments towards the end-of-life. We elucidate how the biomedicalization of end-stage cancer patients has become a multifaceted barrier for patients who could benefit from hospice.

Biomedicalization recognizes the political and economic forces that sustain the technoscientific transformation of the human body; however, less attention has been paid to the ways in which sociocultural values are necessary to create and preserve biomedicalization processes. To capture the sociocultural context surrounding the biomedicalization of end-stage cancer patients, we apply the 'political economy of hope,' a concept originally developed by Mary-Jo Delvecchio Good et al. (1990) and Carlos Novas (2006). The 'political economy of hope' is a descriptive term for how personal endeavors and collective 'hope' for a better future are associated with the broader sociocultural, political and economic processes involved in the enterprise of biomedicine (N. Brown, 2005; Novas, 2006). Biomedicalization and the 'political economy of hope' overlap in their depiction of the collective political economy of stakeholders participating in the technoscientific transformation of the body as a space for biomedical intervention and commodification. The inclusion of 'hope' in our research highlights the agency of patients, patient populations, and providers within the context of EOL decision-making and elucidates how their agency contributes to the production of new biomedical knowledge. As biomedicalization generates new opportunities for technoscientific intervention and commodification, U.S. sociocultural conditions simultaneously nurture a shared 'hope' that aggressive interventions at the end of life will deliver a cure. The circumstances of EOL decision-making and hospice underutilization provide a case study to examine the dialectical relationship between biomedicalization theory and the political economy hope. The 'political economy of hope' augments our understanding of the complex factors involved with biomedicalization and makes it possible to appreciate how previously identified barriers to hospice are interconnected and embedded within a larger and multifaceted structural impediment to hospice utilization.

1. Previously identified barriers to hospice care

An overwhelming majority of Americans express a desire for home palliation and a preference to die at home (Finestone and Inderwies, 2008). US hospice care refers to palliative treatments and other supportive services offered through either in-home or inpatient care to patients within six months of death and their families. Despite the known benefits of hospice care for end-of-life patients, only about twenty-five percent of all terminal cancer patients actually die at home (Teno et al., 2013). For end-stage cancer patients, this paradox of hospice underutilization is provocative, especially considering the increasing number of cancer patients receiving aggressive treatments towards the end of life, including chemotherapy treatments just two weeks or less before death (Earle et al., 2008; Prigerson et al., 2015).

Researchers from a wide array of disciplines identified a range of hospice care barriers relating to end-stage cancer patients. Several studies suggest that physician characteristics are often one of the strongest predictors of hospice enrollment (McGorty and Bornstein, 2003; Obermeyer et al., 2015; Ogle et al., 2002). For example, physicians may have difficulties communicating end-of-life conversations, challenges in developing accurate prognoses for terminal patients, and perceptions of hospice as inflexible when it comes to availability of treatment options (Jenkins et al., 2011; McGorty and Bornstein, 2003; Ogle et al., 2002). Timing of hospice conversations with patients and families is also challenging (Christakis and Iwashyna, 1998; Ogle et al., 2002) because physicians are often concerned that if these conversations are initiated too early they will be perceived as letting their

patients down or, in the US, as a cost saving measure (Brickner et al., 2004).

It is in this context that researchers discuss challenges related to 'inflection' in end-stage cancer treatment, a point in time when disease-modifying therapies are no longer effective and discussion of hospice care as a treatment option would be a logical next step (Aldridge and Kutner, 2015). As we observe in our results, identifying when disease-modifying treatment is no longer effective and pivoting to palliative-only measures rarely takes place simultaneously for end-stage cancer patients. Researchers often focus on physician difficulties prognosticating death within six months to explain why an immediate pivot from active to hospice care does not occur (Jenkins et al., 2011; Lamont and Christakis, 2002). However, this research overlooks additional factors that stall the prognostication process and create separation between recognition that active treatment is no longer effective and discussion of hospice (Spencer et al., 2017). In our results, we elaborate on how external factors associated with physician characteristics contribute to physician indecision around the inflection point.

In contrast to studies examining physician characteristics, others have investigated patient characteristics related to hospice underutilization. Generally, we know that hospice is utilized more often by individuals with higher education, higher income and females (Fishman et al., 2009; Johnson et al., 2008). Many explain disparities in hospice utilization as the result of cultural differences relating to trust in the healthcare system (Johnson et al., 2008) or economic factors leading individuals to perceive hospice as a more expensive healthcare option (Fishman et al., 2009). Some have focused on psychosocial and behavioral characteristics that connect patients' and caregivers' emotional readiness for hospice care with hospice utilization. For example, in a study examining medical doctors' perspective on late referrals to hospice, most physicians explained delays as a product of patient and caregiver reluctance to admit that death was imminent (Jenkins et al., 2011; Vig et al., 2010). Similar studies reveal patient and family misconceptions of hospice as a service only appropriate in the last hours and days prior to death (Vig et al., 2010). In summary, most of these previous examinations of patient and provider characteristics associated with hospice utilization frame hospice underutilization as a challenge overcome by improving patient and physician education and communication about hospice services.

The above issues are complicated in the US by current hospice reimbursement policies, including the Medicare Hospice Benefit (MHB), which are available to individuals with a life expectancy of six months or less and willing to relinquish insurance coverage for 'active,' disease-modifying, treatments (Bogasky et al., 2014). In lieu of active cancer treatment, hospice care provides patients with comfort and palliative treatments focused on relieving pain and other symptoms of the illness and increase the patient's overall quality of life, which are covered on a per-diem basis for every day a patient is served (Ata et al., 2010). Unfortunately, the current structure of hospice reimbursements sets up what others have called the 'terrible choice' because the decision between continuing active treatments or choosing hospice care can be arduous for patients and their families (Lupu et al., 2014). Many have suggested increasing the MHB per-diem rate to alleviate financial losses due to high cost hospice patients such as end-stage cancer patients, but also make the hospice enrollment decision less complicated for end-stage patients (Aldridge et al., 2015; Aldridge and Kutner, 2015; Friedman et al., 2002; Vig et al., 2010). Their primary argument is that changing the MHB reimbursement structure will enable patients to gradually transition from curative to palliative-only treatments, eventually increasing the usage of hospice care by patients at the end of life.

Researchers have noted the lack of an organized synthesis describing how barriers identified in previous studies articulate across all domains (Aldridge et al., 2015) and have called for further research to better understand the longitudinal and interdisciplinary process of decision-making in palliative and hospice care (Belanger et al., 2010). Making this call to action problematic is the current discourse on

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