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'It's time she stopped torturing herself': Structural constraints to decision-making about life-sustaining treatment by medical trainees

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ABSTRACT

This article explores how structural factors associated with the profession and organization of medicine can constrain internal medicine residents, leading them to sometimes limit or terminate treatment in end-of-life care in ways that do not always embrace patient autonomy. Specifically, it examines the opportunities and motivations that explain why residents sometimes arrogate decision-making for themselves about life-sustaining treatment. Using ethnographic data drawn from over two years at an American community hospital, I contend that unlike previous studies which aggregate junior and senior physicians' perspectives, medical trainees face unique constraints that can lead them to intentionally or unintentionally overlook patient preferences. This is especially salient in cases where they misunderstand their patients' wishes, disagree about what is in their best interest, and/or lack the standing to pursue alternative ethical approaches to resolving these tensions. The study concludes with recommendations that take into account the structural underpinnings of arrogance in decision-making about life-sustaining treatment.

The classic social contract for being sick involves seeking competent help for medical problems and following doctors' orders without question. In return, patients expect physicians to serve their best interests and act with professional expertise (Parsons, 1951). This model prevailed unchallenged for nearly a century, partly a consequence of an imbalance in knowledge, and hence power, between patient and physician. Several decades ago, however, that relationship began to transform. The civil rights movement contributed to the deprofessionalization of doctors, or the loss of trust and prestige, by equating beneficence with paternalism, now a pejorative term (Rothman, 2001), and construing patient autonomy as an emancipatory force against physician' authority (Zussman, 1992). The rise of the information age has allowed patients to become informed consumers in the medical decision-making process (Jutel and Dew, 2014), even resulting in laws codifying patients' right to self-determination in end-of-life care (e.g. demanding or refusing resuscitation) through the American Patient Self-Determination Act (PSDA) of 1991 (Luce and Alpers, 2001).

However, despite important strides in patient self-determination, studies find that discrepancies between patient preferences and physician practices persist, especially in end-of-life (EOL) care (Covinsky et al., 2000; Yuen et al., 2011). Scholars of EOL decision-making point to structural factors, such as insurance reimbursement schemes, which constrain physicians' actions and can lead them to overlook patient preferences (Drought and Koenig, 2002; Kaufman, 2005). However, few studies examine the unique constraints facing postgraduate medical trainees (known as residents in the United States) as they simultaneously negotiate competing norms, values, and roles which can take precedence over patient autonomy. Residents are constrained differently than senior physicians because of their junior role in the institutional hierarchy and because they are actively establishing the contours of their medical and ethical practices. In many institutions, residents are also the primary caregivers—and by extension, decision-makers—in end-of-life care, making them especially important to study independently from senior doctors. The high social valence associated with end-of-life, not to mention the considerable costs dispensed during the last year of life (up 25% of all Medicare expenditures (Riley and Lubitz, 2010)), make end-of-life care an especially important period where sensitivity to decision-making processes should be paramount. This article therefore adds to a growing literature on the contextualization of medical decision-making by asking, under what conditions do internal medicine residents limit or terminate treatment without respecting patient wishes?

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1. Theoretical background

1.1. Discrepancies between patient preferences and clinical practice

Shared decision-making, where an interdisciplinary medical team makes decisions with the patient, is an important aspect of high quality end-of-life (EOL) care according to patients (Singer et al., 1999). It is considered a pivotal characteristic of a 'good death' (Frank, 2009) and has been officially recommended as a best practice by critical care experts (Carlet et al., 2004). Even so, studies find that patients are infrequently consulted about their EOL preferences, and when they are consulted, their wishes often go unrecognized (Covinsky et al., 2000). For example, the 1995 SUPPORT Study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) found that fewer than half of all physicians were aware of their patients' resuscitation preferences—and this remained completely unchanged despite a USD$29 million intervention aimed at improving end-of-life care coordination and communication (The SUPPORT Principal Investigators, 1995). Enhanced documentation of patient wishes (including an increase in advanced directives) was virtually ineffective at providing care that was more consistent with patients' wishes (Covinsky et al., 2000; Teno et al., 1997). Perhaps even more troubling is that in the 20 years since the SUPPORT study, EOL communication has not significantly improved (Uy et al., 2013; Yuen et al., 2011), and serious discrepancies between patient preferences and clinical practices persist (Carlet et al., 2004; Farber et al., 2006).

European studies reveal that this trend extends beyond the United States. In Belgium, half of all patients in one study were excluded in end-of-life decisions (including ones aimed at shortening patients' lives), even when those patients had explicitly stated that they wanted to be involved (Pardon et al., 2012). Similarly, almost all patients wanted their families to be involved EOL decisions if they lost competence, but this only happened in half of cases. The authors called for further research into why willing patients are not more involved in EOL decision-making. In other words, why do physicians arrogate these decisions for themselves, despite advancements in patient autonomy?

1.2. Why do doctors sometimes disregard patient preferences in EOL care?

In his eponymous essay, physician Ingelfinger (1980) referred to arrogance in the medical profession, not in the traditional sense of conceit, but as in 'to arrogate,' that is, to claim a right that belongs to another. He maintained that a degree of arrogance was integral to the good practice of medicine: "A physician who merely spreads an array of vendibles in front of the patient and then says, 'Go ahead and choose, it's your life,' is guilty of shirking his duty, if not of malpractice" (Ingelfinger, 1980, p. 1509). Importantly, he distinguished between beneficial and destructive arrogance, depending on whether this domination was combined with empathy. For Ingelfinger, beneficial arrogance emerged from individual doctors making decisions that were in the best interest of their patients (what some might call paternalism). In contrast, more recent reflections by physicians point to the structural sources of arrogance. Time and economic pressures from insurers and medical administrators have fostered what some have termed 'system arrogance,' where patients are viewed "simply as a job to be done cost-effectively" (Berger, 2002, p. 146). In the process, their preferences get overlooked.

Without explicitly referring to the medical arrogance literature, studies have found that systemic-level factors, more than individual ones, affect the quality of end-of-life care, including physicians' likelihood of overlooking patient preferences (Drought and Koenig, 2002; Yuen et al., 2011). In her masterful ethnography, anthropologist Kaufman (2005) writes about how death in hospitals has been transformed into a structured and timed event. Her work illustrates how patients are viewed by medical professionals through the lens of having to move through time with economic and clinical efficiency. In this way, the hospital 'machinery' of billing, efficiency, and medical supplies shapes practices in ways that extend beyond individuals' control. For example, one study found that place of death (e.g. hospital vs. hospice) had more to do with bed availability than physician or patient preference (Freeborne et al., 2000).

Physician' actions are further constrained by professional relations, limited prognostic information, demands from patients' families and legal repercussions (Marco et al., 2009). Some have argued that the SUPPORT intervention failed because it targeted individual behaviors rather than the systemic factors which constrain end-of-life care, including 1) a medical culture favoring technological intervention, 2) inadequate hospital standards regarding resuscitation discussions that do not hold physicians accountable, 3) insufficient training of medical professionals and 4) reimbursement schemes that incentivize volume and intensity of care rather than patient satisfaction (Yuen et al., 2011). Similarly, Kaufman (2005) noted that physicians face competing imperatives of professional autonomy, a market-oriented healthcare system and triumphalist goals of modern medicine—all of which affect resuscitation decisions and conversations with patients.

1.3. Social structures constrain different social actors differently

It follows that if institutional structures constrain medical actors, then actors with different roles might be constrained differently (Bosk, 1979 [2003]; Chambliss, 1996). Research on medical decision-making, especially in end-of-life and critical care, finds that physicians struggle considerably against various encroaching actors (nurses, patients and family members) to maintain their discretion over treatment decisions (Anspach, 1993; Chambliss, 1996; Heimer and Staffen, 1998; Timmermans, 1999; Zussman, 1992). This body of research emphasizes that individuals make decisions based on their position in the social structure. For example, Anspach (1993) argues that patients and situations look different to people in different positions, such that a sick infant might be perceived differently by a nurse than by a parent.

Despite considerable advances in the contextualization of medical decision-making, however, sociological research has not adequately considered how constraints facing medical professionals might vary at different stages of their career. Instead, studies often aggregate senior and junior physicians' perspectives and contrast them to other health providers' or patients' (Anspach, 1993; Heimer and Staffen, 1998; Kaufman, 2005). There is however convincing evidence that residents should be considered independently of their more senior counterparts. For example, residents are not as concerned about lawsuits since senior attending physicians ("attendings") are legally responsible for patient care. However, they may be more concerned about stepping 'out of line' when disagreeing with superiors, given their junior status.

Furthermore, residents and attendings are known to exhibit different attitudes towards EOL care decision-making. In one study, attendings were significantly more likely to comply with hypothetical patient requests for withholding or withdrawing life-sustaining treatment than residents (Thomas et al., 2014). The authors suggested that clinical experience was driving the difference and notably found a change in residents' attitudes as they gained experience. However, they did not observe physicians' practices in real-time (they relied on hypothetical vignettes) and only considered respondents' willingness to comply with requests for