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Homing in on the Social: Systems-level Influences on Overly Aggressive Treatments at the End of Life

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Abstract

Context: The American medical system is programmed to a default setting of aggressive care for the terminally ill. Institutional norms of decision-making have been shown to promote high intensity care, regardless of consistency with patient preferences. There are myriad factors at a system, clinician, surrogate, and patient level that drive the culture of overly aggressive treatments in American hospitals.

Objective: To understand physician perspective of the ways systems-level factors influence patient, physician, and surrogate perceptions and consequent behavior.

Methods: Semi-structured in-depth qualitative interviews with 42 internal medicine physicians across three American academic medical centers. This qualitative study was exploratory in nature, intended to enhance conceptual understanding of underlying phenomena that drive physician attitudes and behavior.

Results: The interviews revealed many factors that contributed to overly aggressive treatments at the end of life. Systemic factors, which describe underlying cultures (including institutional, professional, or community-based cultures), typical practices of care, or systemic defaults which drive patterns of care, manifested its influence both directly as well as through its impact on patient, surrogate, and physician behaviors and attitudes.

Conclusion: Institutional cultures, social norms, and systemic defaults influence both normative beliefs regarding standards of care and treatments plans that may not benefit seriously ill patients.

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Keywords

overly aggressive treatments; end-of-life care; qualitative research; social science; medical culture

Background

A good end-of-life experience – a death free from avoidable suffering and distress for patients and their loved ones and aligned with patients' preferences - remains elusive[1,2]. Although the majority of Americans want to die comfortably at home rather than hospitalized on life support[2], the medical system defaults toaggressive care for the terminally ill[3,4]. Despite advances in palliative care, the past decade has seen increased intensive care unit (ICU) usage and health care transitions in the last month of life[3]. Compared to a decade ago, patients with advanced dementia are twice as likely to receive mechanical ventilation without substantial improvement in survival[5].

Overly aggressive treatments have been defined in various ways. The American Society of Clinical Oncology has defined them as emergency, hospital or ICU visit in the last month of life, chemotherapy in the last two weeks of life, and underutilization of hospice[6,7]. Aggressive treatments that are not aligned with patient preferences nor in the patient's best interest have been linked to poor quality of care, reduced quality of life near death, and low-value care[7–11]. Caregivers suffer negative consequences of depression and PTSD[12–15]. Physicians and nurses experience moral distress over perceived futile care[16,17].

Research regarding interventions designed to improve end-of-life care, including video-based decision aids, simulation-based communication skills training, proactive palliative care consultation, and palliative care led ICU family meetings, have provided mixed results [18–22]. Taken together, these trends suggest that factors beyond the dyadic decision-making process impact ongoing struggles to improve end-of-life care. Institutional norms of decision-making have been shown to promote high intensity care, regardless of consistency with patient preferences[2,23]. We know little about these institutional norms and how they may undermine interventions designed to improve end-of-life care.

These interventions commonly focus on individual behaviors and micro-level interactions between the patient, surrogate, and clinicians. There is a need for more exploratory studies targeting the institutional causes of overly aggressive treatment at the end of life and how theyinfluence individual behaviors. In this paper, we use qualitative interviews with physicians to explore how systems-level factors influence physician, patient, and surrogate perceptions and consequent behavior.

Methods

Design:

Semi-structured in-depth interviews investigated whether physicians believed they were acting in a patient's best interest when pursuing resuscitation at the end of life. This research emanates from the sociological tradition of interpretivist symbolic interactionist approach[24], which explores how individuals and systems interact and influence each other. Although the

focus of the study was on resuscitation, discussions included end-of-life care more broadly. Overly aggressive treatment at the end of life emerged as a major theme. Themes that emerged from initial interviews were refined and explored in subsequent interviews through directed questions.

Physician Sample:

One investigator (ED, a physician and PhD candidate in Sociology) recruited and interviewed general and subspecialty internal medicine physicians in person and via Skype (two people) at three academic medical centers in New England, the Mid-Atlantic, and the Pacific Northwest. Physicians were purposively sampled by years of experience and medical subspecialty to provide a diverse range of perspectives and contribute to understanding emerging patterns and themes. Recruitment occurred through group e-mail solicitations, individual requests, and snowball sampling. Of those who received individual solicitations, no one declined participation though a small subset did not respond or was unable to participate due to scheduling difficulties.

To provide thematic continuity, an interview guide used across all sites (see appendix). An open-ended interview format was used to, encourage participants to organically explore topics they deemed most relevant. Following an informed consent process, interviews lasted between 45 and 120 minutes. They were subsequently anonymized, audiotaped, and transcribed. Theoretical saturation, a point where no new themes arose from the interviews, was achieved, at which point data collection ceased.

Analysis:

This study reflected a qualitative approach that acknowledges the intrinsic nature of multiple perspectives to the research process. [25–27]. As such, it was important that the research process recognize bias through rigorous reflexivity, understanding how our own clinical experiences both inform and potentially bias our interpretation of the data. Data were analyzed and themes were developed concurrently as more interviews were conducted, coded, and input into Excel. Established themes then became the subject of probes in subsequent interviews to further confirm the trustworthiness of the data. Rigor was maintained by analyzing disconfirming cases in light of their effect on emerging theories. Member-checking was done through informal conversations and formal presentations with physicians of similar background to the respondents, as well as formal presentations with several study participants in the audience with feedback from the audience and specifically the study participants as to the veracity of the findings.

Using thematic analysis, two independent coders (ED and AC, a medical student and Masters student in Philosophy) identified key themes throughout a subset of the interviews through an iterative process. These themes were entered into the codebook[28]. 20% of the interviews were subsequently coded, where emerging themes and patterns were discussed. Disagreement was rare amongst coders. One researcher (ED) then coded the remaining interviews and added additional themes and categories to the codebook as needed. The Johns Hopkins University Institutional Review Board approved this study.

Results

One investigator (ED) interviewed forty-two hospital-based internal medicine physicians (Table 1). Because similar themes and patterns emerged in physician responses across all sites, we based our assessment of theoretical saturation on the aggregate interviews.

The interviews revealed many factors that physicians perceive to contribute to overly aggressive treatments at the end of life. Systemic factors, which describe underlying cultures (including institutional, professional, or community-based cultures), typical practices of care, or systemic defaults which drive care patterns, manifested its influence both directly as well as through its impact on patient, surrogate, and physician behaviors and attitudes. A full list of themes that arose is listed in Table 2.

Direct Impact of Systemic Factors

The cultural milieu that patients, surrogates, and physicians operate within affects individual practices and behaviors. As the empowered actors within the hospital system, physicians are the primary modality by which these systemic factors are expressed. As such, this section also includes systemic factors that influence physician behavior and attitudes. Because several individuals and teams are involved in each patient's care, it is difficult for an individual person to resist a default of aggressive interventions:

"I think that there's just this idea that the default is go, go, go, and if anyone wants to keep going then you have to keep going…[but] everyone has to agree to stop with further measures." (A15)

"I think there's sort of an unstated agreement. We came to the hospital to get well, we're not ready to die, you have lots of resources and you're going to use them. That's the expectation. When is it time to take a step back and…assess whether we've done the right or wrong thing? Who has ownership? The patient or the doctor?" (B2)

Societal norms in America also contribute to the drive towards aggressive care; they frequently reflects values of liberal individualism and the primacy of choice, which is oftentimes equated with autonomy:

"There are times when…it's a bad death. I am frustrated by…the fact that autonomy drives the system including matters such as doing CPR (cardiopulmonary resuscitation) on a patient who is hopelessly ill - CPR I don't feel is indicated." (A3)

"We felt there was nothing more to be done. He and his family didn't want to hear it. They insisted and brought us the patients' bill of rights." (A14)

In the first quote, autonomy drives inappropriate resuscitation whereas in the second quote, autonomy is used as a means of empowering patients in conflict with the physician's perception of appropriate care, to the dismay of the physician.

Workflow pressures and competing demands on physicians' time are additional barriers to having goals of care conversations. Mitigating aggressive treatments require time and

engagement; goals of care conversations are dis-incentivized due to lack of time and are inconsistent with the institutional pace of care. Although this is a logistical challenge, this institutional reality subsequently serves as justification for a cultural primacy of an unreflective conception of autonomy rather than making time to have in-depth conversations to achieve consensus:

> "There were several pressures to not have that conversation in depth. One was just a time pressure...You have less time than you had before [due to pressure to discharge and admit and electronic medical records]. conversations that require time, [are] hard. I try to at least briefly let the family and patient know that I think this would do more harm than good, but I also let them know that it's their decision. In the past, I had been more aggressive about getting the ethics consults. Now, I've given up because of the time constraints." (A7)

Oftentimes hospital workflow defaults to of aggressive treatments. Interviewees described a fast-paced treatment decision-making process that did not leave time to reflect upon whether individual treatments would be of benefit to the whole patient:

> "The typical patient is post-arrest. The patient is being cooled in an ICU. After a certain point, there's some neurological recovery. We're not sure about the neurological recovery but in the meantime, the creatinine is this or the potassium is that. We start CVVH (continuous veno-venous hemofiltration) until we determine, so we sort of get stuck and we take that path. Suddenly, we have a vegetative patient on CVVH." (B2)

The modern, systems-focused nature of hospital care is only possible due to the technologies available. An important systemic factor that contributes to aggressive care is the allure of high-technology interventions and the technological imperative, where there is an inevitable impetus and momentum to adapt new technologies[29]. Technology transitions from a novelty towards an expectation:

> "I think that people that put their foot down are few and far between whereas people that are full court press just because we have so much technology…that sets up a totally different expectation that all these people who had been coded at outside hospitals who had died…are being "crashed to ECMO (Extracorporeal Membranous Oxygenation)'."(B11)

> "Just because you can do it, you're doing more…the practice [here] is put [people] on ECMO and then ask the questions…that's how we perceive technology right now…It's hard to give up on doing more because we're a very technology oriented society. We fix problems." (A8)

Acknowledging and communicating that a patient is dying can also be difficult for physicians. Physicians' behaviors in part reflect institutional, departmental, and sub-specialty cultures, as well as challenges accepting and preparing for death.

> "Frequently the patient is dying but none of the patient's doctors told the patient, 'Look, you have some serious problems and let's talk about how you can deal with this in a comfortable way, rather going through the vortex of escalating care'." (A3)

> "…Oncology attendings [have been] really upset that I brought up goals of care, even upset that I confirmed code status. I was taken aback when [on] the oncology service…[I] had multiple patients where the patient and the families were on board with comfort care…[while the attendings were] not. That can be very difficult as a resident." (B13)

Discussing topics that may upset patients such as death is difficult for clinicians. Fear of litigation was noted as a factor, but more frequently a greater concern was a desire to avoid unpleasant confrontation:

> "We still escalate care. I think you just push ahead…when the patient can't make the decision. I have been by many, that the hospital does not want to create a scene. They never say lawsuit. You do not want to upset the family members for even patients who are in all senses dead already. And so you just, if the family still pushes for it to go ahead, do as much as you do, not necessarily wanting to." (B11)

Systemic Factors Evident in Individual Patient or Surrogate Behavior and Attitudes

Facing one's own mortality can be an emotional shock to patients. Adaptation of a "fighter" mentality can give patients strength to battle illness, but can also lead to unwitting requests of futile measures. Physicians do not know how to address potentially inappropriate care when they perceive patients as "fighters":

> "The sorts of things that make me uncomfortable are 'I'm a fighter, I want to get the most aggressive care humanly possible every step of the way and I don't want to discuss it.'" (A6)

Systematic and structural racism in American society and in the history of medical research and practice[30,31] have engendered distrust of the health care system. Physicians perceive these histories to have a profound effect on end-of-life decisions:

> "What I found is that certain groups, such as African-American families, tend to be much more distrusting of the DNR (Do-not-resuscitate) order, and much more aggressive about making sure that they stay full code." (A7)

> "There's a large Ethiopian and Somalian population around this area. I've had families tell me that their loved ones want to be DNR but their families absolutely refuse to allow it. Once they are no longer able to make their own decisions, they quickly reverse their loved one's wishes…People in their community [and] church…told them, 'don't let the doctors kill off your loved one' because they're poor and black and don't speak English." (C7)

A patient's religious convictions also play a role in end-of-life decision-making. As important are physician's perception of the family's religious beliefs which influence how they approach end-of-life conversations:

> "The Orthodox Jewish community is never going to sign a DNR. I'm not going to bring [them], no matter what, to the hospital ethics committee because that's their religious belief." (B7)

> "No religion on earth prescribes CPR. We had people here of all religions and denominations, and with the help of their appropriate religious leaders as well as our ethics committee we have got them to the proper decision including CPR or no CPR…I've had at least two cases that I recall that [an Orthodox Jewish] patient was DNR…." (B5)

The respondent in the first quotation stated that they would never bring up DNR with an Orthodox Jewish family due to his preconceptions of the religion whereas the respondent in the second quotation had the opposite view, that with the right community support, a DNR decision could be considered.

Discussion

Interviews generally reflected a default to aggressive treatments that has been noted in the literature[2,32,33]. Decisions to provide overly aggressive treatments in the hospital are embedded in a cultural milieu influenced by a variety of systemic factors that structure the relationships among clinicians, patients, families, and surrogates. The systemic factors are visible in the policies, finances, resource pressures, institutional leadership, and patient and family factors that surround hospital-based end-of-life care.

Kaufman argues that individual decisions are often not actually decisions, but are instead determined by the structural pattern of the hospital system, which compels particular decisions upon both clinicians and patients while supporting a false illusion of choice[32]. The quotations above demonstrate that multiple factors compel certain types of decisions in the ICU, despite the best intentions of the individuals involved in the decision-making process. Strategies to reduce burdensome treatment thus must look beyond individual decision-making to consider how systematic factors in the healthcare system could be engaged.

The ideology of choice and patient autonomy at the end of life reflects a traditionally American ideology of individual liberty[34], but sometimes this choice is an illusion. In a previously published paper, we described how physician trainees at autonomy focused hospitals possessed an unreflective belief in the primacy of autonomy and felt obligated to offer choices that they neither desired nor believed would benefit the patient[35]. The irony is that these physicians feel they are providing a false or forced choice since successful resuscitation might not be physiologically possible. Even if surrogates wish to de-escalate care at the end of life, they may find it very difficult to decline treatments offered, lest it be perceived as "killing" their loved one.

Patient preferences frequently reflect social norms and values, which shape perceptionsof what should be valued at the end of life. Physician respondents described a "fighter" mentality that encouraged an attitude of never giving up. However, health care systems may be complicit in encouraging that attitude. One study noted that direct-to-consumer cancer center advertising capitalized on emotional appeal, frequently "evoking hope for survival, describing cancer treatment as a fight or battle, and inducing fear"[36].

Similarly, physician communications might reflect their own biases and perceptions. The respondents' pre-established biases and assumptions, such as that of the patient's religious

beliefs, influence their interactions, communications, and ultimately outcomes of their patients. This highlights the need to consider actions and behaviors not in isolation, but as a consequence of an individual's perception and interpretation of systemic factors.

The unspoken pact that patients entrust doctors to their care in order to avoid death, belies the very notion of accepting death as a natural and inevitable process. The default towards aggressive care described by several respondents reflects the extreme difficulty individuals encounter when they try to resist these forces[37]. The multi-specialty team-based nature of the health care ecosystem means that individuals rarely have the power to resist, as multiple parties must agree to de-escalate care. Associated systemic forces include a lack of time and decision-making heuristics that favor treating individual organ systems as they fail rather than a more holistic approach. The allure of new technologies in combination with patients' fear of death results in ever-escalating interventions where the goal of person-centeredness is forgotten for the sake of longevity[33,38,39].

There are societal, patient and professional concerns about overly aggressive treatments, and yet individual actors within the hospital find themselves swept towards it. This speaks to the strength of cultural norms and a system that unwittingly promotes aggressive care regardless of whether it is goals aligned or evidence based. Though patients, surrogates, and physicians act autonomously, individuals are all embedded within the social system. In essence, we have inadvertently set ourselves up to promote aggressive care. As Figure 1 illustrates, these defaults and norms arose from the aggregate actions of individuals, all of whom have their own motivations, incentives, and experiences that shape their perception of the world and their way of acting within it[40]. This model derives from Antony Giddens' structuration theory, which theorizes how myriad factors become interlinked to form an individual actor's aggregated perception of the world. The resulting system that we created has unintended consequences which further ingrain these norms and defaults towards aggressive care.

Many efforts to improve the quality of end-of-life care have focused on modifying individual clinician behaviors, but these findings highlight the need to attend to the broader system of care within which individual decisions to provide overly aggressive treatments are made[18,20]. Appreciating howan individuals' perception, interpretation of systemic factors, and consequent behavior is influenced by social norms represents an important first step in developing approaches to mitigate unwanted aggressive care.

Perhaps the reason why individual clinician-focused interventions are less effective than expected against this issue, despite the agreement by so many that aggressive care at end of life is problematic, is because all of the factors are socially embedded. This makes it difficult to change any one in isolation or with much effect on the overall pattern of care. As such, descriptive studies and interventions must explore root causes of behaviors and how that influences an individual's ability to make these kinds of choices. Interventions that target culture change are complex, and will require creative and holistic innovation. Insights might be drawn from fields such as behavioral economics, sociological theory, and design thinking, including further empirical analysis of the role of structuration theory in clinicians' perceptions and its contribution to a culture of burdensome care[40]

Limitations

A limitation of this study is that only physicians were interviewed. The data did not capture the voices of patients, families, nurses, administrators, or any other relevant individuals who would have an informed perspective on the provision of overly aggressive treatments. In addition, interviews (as opposed to direct observation) describe physicians' attitudes and beliefs rather than actual practices. This study sampled physicians from academic medical centers in urban environments, which likely have different pressures and incentives towards aggressive care in comparison to community hospitals, hospitals in rural areas, and other hospitals of differing characteristics.

Conclusion

There are myriad factors at a system, clinician, surrogate, and patient level that drive the culture of overly aggressive treatments in American hospitals. Yet, it is crucial that these myriad factors be considered in terms of how they connect and reinforce each other as a 'stable' social system to create the behavior of unwanted and unwarranted aggressive care at end of life. This research suggests that institutional cultures, social norms, and systemic defaults influence both normative beliefs regarding standards of care and treatments plans that may not benefit seriously ill patients. Further study is needed to develop a comprehensive understanding of the complex socio-cultural factors that drive intensity of care and identify clinical and policy interventions that can help match intensity of care with patients' informed goals of care.

Acknowledgements:

Appendix 1: Sample interview guide questions

Thinking of a patient where DNR would be appropriate, how would you go about with that conversation.

How often is there a conflict when you say this (again a patient who you think should be DNR)

Have you ever had to do a procedure or CPR that you thought to be against your moral/ ethical beliefs

What is your hospital's culture when it comes to DNR decisions, i.e. what do people usually do?

Think of a case where there was conflict

> How are decisions normally reached regarding a DNR order and by whom?

> Who was this decision discussed with?

> Was there any disagreement and how was that dealt with?

How do you feel about the current approach that you take to DNR orders?

How satisfied are you with the way decisions are reached?

How satisfied are you about the way decisions are discussed with patients/family?

Do you think the current system of DNR practice serves the best interest of the patient?

> If yes, why? If no, why not?

> Why do you think patients full code even if doctors think it's futile?

Are there any situations where you think the current system for DNR does not serve the best interest of the patient?

> Can you tell me why that is?

> What might be a better approach in these cases?

Is DNR a clinical or other decision (legal, personal, opinion?)

Would you feel comfortable making decisions unilaterally? (i.e. UK system)

What do you feel is the role of the patient or family in making DNR decisions? What do you think it should be based on your beliefs? What is it in reality?

How much priority do you think their preferences should have in the decision made? What do you think it should be based on your beliefs? What is it in reality?

To what extent do you feel that a DNR order is a clinical decision?
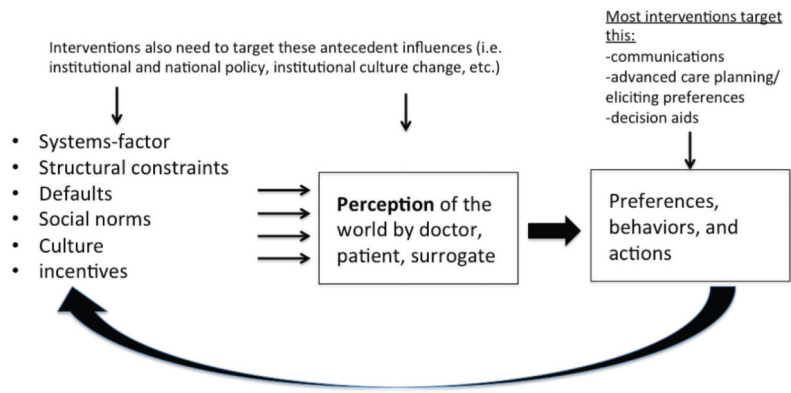
> What is your reasoning behind that position?

Would you feel comfortable making a DNR decision against the patient/family's wishes? Why?

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Interventions also need to target these antecedent influences (i.e. institutional and national policy, institutional culture change, etc.)

Most interventions target this:
-communications
-advanced care planning/ eliciting preferences
-decision aids

- Systems-factor
- Structural constraints
- Defaults
- Social norms
- Culture
- incentives

Perception of the world by doctor, patient, surrogate

Preferences, behaviors, and actions

Figure 1:
Considering how the social system affects perception and behaviors

Table 1:

Demographic Characteristics of Study Participants

	Hospital A (n=13)	Hospitals B(n=16)	Hospital C (n=13)
Years of Experience Range Mean	2–45 12.85	1–42 15.5	2–40 12.85
Male:Female	6:7	11:5	6:7
Professional Status			
Attending	6 (46%)	9 (56%)	5 (38%)
Fellow	3 (23%)	3 (19%)	4 (31%)
Residents	4 (31%)	4 (25%)	4 (31%)
Internal Medicine Subspecialty			
General internal Medicine	5 (38%)	10 (62%)	5 (38%)
Pulmonary/CriticalCare	6(46%)	2 (12%)	6(46%)
Palliative Care	1 (8%)	2 (12%)	1 (8%)
Geriatrics	0 (0%)	0 (0%)	0 (0%)
Oncology	0 (0%)	1 (6%)	1 (8%)
Cardiology	1 (8%)	1 (6%)	0 (0%)
Neurology	0 (0%)	0 (0%)	1 (8%)

Table 2:

Interview themes of factors that contribute to overly aggressive treatments at the end of life

Patient Factors	Surrogate Factors	Physician Factors	Systemic Factors
• Denial of death	• Demanding family	• Difficulties, discomfort, and/or delays delivering bad	• Mistrust that arises from cultural issues
• More difficult when death is unexpected	• Guilt	• Offering "false" choices such as futile therapies or a menu of choices (i.e. offering "everything")	• Cultural norms on death
• Patients saying that want "everything done"	• Misperception that treatment de-escalation is perceived as "killing their loved one"	• Being a "fixer"	• Fear of death in American
• Patient is a "fighter"	• Secondary gain	• Difficulty setting limits	• Default of aggressive care in hospitals
• Religious/cultural factors (also systemic)	• Unrealistic	• Difficulty prognosticating	• Concerns about litigation
• Mistrust of healthcare system (also systemic)	• Surrogates saying that want "everything done" or to "do everything"	• Lack of confidence about medical skills (for trainees)	• Consumer culture that prioritizes patient
	• "California Daughter" (geographically distant family member becoming very involved)		• Technological imperative
			• Issues of time