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## **Habermasian Communication Pathologies in Do-Not-Resuscitate Discussions at the End of Life: Manipulation as an Unintended Consequence of an Ideology of Patient Autonomy**

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### **Abstract**

The focus on patient autonomy in American and increasingly British medicine highlights the importance of choice. However, to truly honour patient autonomy, there must be both understanding and non-control. Fifty-eight semi-structured in-depth interviews were conducted with internal medicine physicians at three hospitals in the US and one in the UK. At hospitals where autonomy was prioritised, trainees equated autonomy with giving a menu of choices and felt uncomfortable giving a recommendation based on clinical knowledge as they worried that that would infringe upon patient autonomy.

Employing Habermas's Theory of Communicative Action, this paper explores how physician trainees' communication practices of using purposefully graphic descriptions of resuscitation to discourage that choice prevent greater understanding and compromise non-control. Central to this problem are also issues of colonisation of the lifeworld by the system. Physicians are fully inculcated in their respect for autonomy but unintentionally resort to strategic forms of communication that prevent patients from adequately understanding their situation because trainees feel constrained against making recommendations. However, if the ideal of autonomy is to be realised, physicians might have to move towards practices that embrace a more authentic autonomy that fosters open communication that allows for co-creation of consensus between doctors and patients.

### **Keywords**

Decisions/decision-making; Doctor-patient communication/interaction; Empowerment; End of life care; Ethics/bioethics; Palliative care

### **Introduction**

Decades ago, the “doctor knows best” attitude prevailed in western medicine. Since then, the pendulum has swung towards honouring patient autonomy in the US and increasingly the UK. These shifts towards autonomy are multifactorial and occurred in part due to criticism

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of physician paternalism, the decline in physician dominance, as well as the corporatization of medicine and the consequent change in the physician-patient relationship towards a more customer-oriented approach (Haug and Lavin, 1979; Wolinsky, 1988; Mckinlay and Marceau, 2002). This paper explores the implications of these changes and considers the tensions they create between acting with beneficence (best interest) and honouring a flawed conception of patient autonomy that occurs in some hospitals.

This focus on autonomy highlights the importance of freedom and choice for patients to make their own decisions based on their goals and values. However, to truly honour patient autonomy, the patient/surrogate must have an adequate understanding of their situation and the choices before them (Faden and Beauchamp, 1986). In addition, other conditions for autonomy to be fulfilled include intentionality and non-control, which includes freedom from coercion and manipulation. This paper focuses on both the understanding and non-control conditions for fulfilling autonomy, and specifically the distinction between persuasion and manipulation.

Persuasion is defined as coming “to believe in something through the merit of reasons another person advances” which must be influenced by appeals to cognition rather than emotion (Beauchamp and Childress, 2013). In contrast, manipulation is incompatible with autonomy because it sways people to do what the manipulator wants, primarily through information manipulation. Although the historic shift away from paternalism was a necessary and positive step, autonomy is sometimes understood in a reductionist way that actually disempowers patients; patients are asked to make choices without the understanding or guidance necessary to make informed choices (Elizabeth Dzeng *et al.*, 2015). Some physicians feel uncomfortable giving a clinical recommendation as they worry that this would infringe upon patient autonomy.

Despite this discomfort, doctors still hold power in the physician-patient relationship and are able to manipulate conversations to sway patients towards a decision that they believe is in the patient’s best interest. Though framing is inevitable, it can be used strategically in ways that obstructs autonomy. This paper explores the ways that physician trainees use purposefully graphic descriptions of resuscitation to discourage choice through the lens of Jürgen Habermas’s Theory of Communicative Action. These manipulative strategies I contend are pathologic and disempowering as they hinder patient autonomy by failing to fulfil the non-control criteria. Central to this problem, are also issues of colonisation of the lifeworld, which encompasses the individual’s lived experience of everyday life by the system, the capitalist bureaucracy. This occurs not only from the patient’s perspective, but also from colonisation of the doctor’s own lifeworld during medical training. Some physicians who feel constrained against making recommendations instead resort to strategic forms of communication. If the ideal of autonomy is to be realised in practice, the medical system may have to move towards practices that embrace a more nuanced form of autonomy that fosters open forms of communication that permit co-creation of consensus between doctors and patients. Communication pathologies are harmful because they may result in treatments that are neither in the patient’s best interest nor consistent with their goals and values.

The specific example used here to explore these issues is the systemic default of offering and performing cardiopulmonary resuscitation (CPR) on terminally ill patients even if they are unlikely to survive resuscitation. A do-not-resuscitate (DNR) order is implemented when it would not be appropriate or desired to perform resuscitation when the heart stops at the end of life. This procedure was first established in 1960 to restart the heart following specific arrhythmias and was very effective in doing so (Cooper, Cooper and Cooper, 2006). Since then, its scope has been expanded to become the default in the hospital for anyone who dies, despite the fact that its efficacy is extremely limited in most medical conditions. CPR is ineffective in terminal illness, as it does nothing to correct the underlying condition that caused the patient to die in the first place.

Resuscitation is not harmless. It requires cracking ribs to pump the heart, inserting invasive lines, placing a tube down the throat to ventilate the lungs, and delivering electric shocks that attempt to restart the heart. The last moments of life are spent receiving aggressive and possibly futile treatment surrounded by clinicians rather than loved ones. Some physicians have argued that ineffective resuscitation should not be offered as it causes the patient undue harm and suffering (Curtis and Burt, 2007; Blinderman, Krakauer and Solomon, 2012).

## **Background: The influence of institutional cultures and policies on physicians' ethical approach to DNR decision-making**

In a previous publication, I found that institutional cultures and policies that prioritised autonomy versus beneficence (best interest) influenced physicians' ethical beliefs and clinical approaches towards DNR decision-making at the end of life (Elizabeth Dzeng *et al.*, 2015). The aim of that study was to explore how an institution's ethical priorities surrounding autonomy and beneficence, as reflected by the institution's culture and policies, influenced physicians' approaches to DNR decision-making conversations. This manuscript builds upon that paper to discuss the implications of physicians' ethical beliefs on end-of-life communication practices. It emerged during the research process, that two of these four hospitals where the interviews were conducted had policies and cultures that prioritised patient autonomy (Hospitals A and B) whereas the other two (Hospitals C and D) had policies and cultures that prioritised decision-making in the patient's best interest. The hospital's prioritisation of autonomy versus beneficence appeared to influence the way that physician trainees conceptualised autonomy. This influenced the degree of choice offered and recommendations made.

Trainees at autonomy-focused hospitals appeared to have an unreflective deference to a flawed notion of autonomy and felt compelled to offer the choice of resuscitation neutrally in most situations regardless of whether they believed resuscitation to be clinically appropriate. In contrast, trainees at beneficence-focused hospitals appeared more comfortable recommending against resuscitation when survival was unlikely. Recommendations that reflect medical expertise and experience are important to help guide informed decision-making. Similarly, experienced physicians (i.e. consultants (UK) or attendings (US)) at all sites were willing to make recommendations against futile resuscitation (Dzeng *et al.*, 2015). That attending physicians at all four sites were willing to

make recommendations suggests that further years of experience and training mitigate the effects of hospital culture.

The aim of this paper is to provide a normative argument that Habermasian communication pathologies in end-of-life discussions are manipulative and hinders patient autonomy and the co-creation of consensus between the physician and patient/surrogate. An impoverished understanding of autonomy embedded in institutional culture encourages the use of these communication pathologies, which in turn compromises true autonomy.

## Methods

Three large academic medical centres with well-established teaching programs in the US (New England (Hospital A), Mid-Atlantic (Hospital B), and Pacific Northwest (Hospital C)) and one in the UK (Hospital D) were purposively sampled based on expected differences in hospital culture and variations in hospital policies (See Table 1). Please refer to the publication by Dzeng *et al.* (2015) for further details on the evolution of the rationale of the study and for an explanation of site selection. The rationale for inclusion of the UK site was to cover the entire spectrum of decision-making by including a model of decision-making not available in the US.

Between March 7, 2013 and January 8, 2014, fifty-eight general and subspecialty internal medicine physicians were recruited and interviewed by the author. Thirteen to sixteen physicians participated at each site. Respondents were selected based on years of experience and medical subspecialty to provide a wide range of perspectives and contribute to understanding emerging patterns and themes (See Table 2). Recruitment occurred through group e-mail advertisements, individual solicitations, and personal referrals.

The initial empirical focus for the overall project aims developed during the author's clinical training. Literature review on palliative care best practices and medical sociology in the years following that clinical training allowed her to reflect critically on observed culture surrounding end of life communication described in this paper. Initial pilot fieldwork commenced where it inductively emerged that a Habermasian framework would be useful. Ongoing fieldwork and data analysis subsequently focused on these Habermasian themes. An interview guide used across all sites provided thematic continuity. The interview format was open ended, encouraging participants to explore those aspects they considered most relevant. Interviews lasted between 45 and 120 minutes and were audiotaped and transcribed verbatim. Data collection concluded when theoretical saturation emerged, the point where no new themes arose from the interviews.

The author analyzed the data systematically using thematic analysis. Two independent readers (ED and AC) identified initial key themes that occurred through a subset of the interviews and developed a codebook through an iterative process. They subsequently coded 20% of the interviews, discussing emerging themes and patterns. There was rarely disagreement amongst coders. The author then analysed and coded the remaining interviews using the codebook and added additional themes and adapted categories as needed. Informed consent was obtained from all interviewees and interview data were anonymised during

transcription. The study was approved by the Johns Hopkins Institutional Review Board and the UK National Health Service (NHS) National Research Ethics Service.

## Empirical Findings Demonstrating Manipulative Communication Practices

Trainees at autonomy-focused institutions tended to have a reductionist interpretation of autonomy primarily to mean giving choice. These trainees felt that there was no role for reasoned persuasion and felt that options must be presented in a way they perceive to be neutral. As such, they refrained from giving a recommendation whether resuscitation would benefit the patient. However, because they still had a clear sense of what they believed was clinically appropriate, conversations were framed in different ways depending on the circumstance:

“I have noticed a grab bag of things people can now offer, like a buffet... I really don't understand how we have gotten to that point. I think physicians don't really present [it] the same way each time. We present code status (resuscitation status) differently. We may use different language and we can make things very graphic if we want to...I get pretty disturbed with how I see it presented” (Hospital A, Post-Graduate Year 2 (PGY-2): 12).

Using graphic descriptions of resuscitation to convince patients/surrogates to decline resuscitation is a common strategy by trainees at autonomy-focused institutions when they believe resuscitation is not clinically appropriate. These respondents emphasise providing choice and the importance of not providing their “opinion” by making a clinical recommendation. Instead, their approach took on this form:

“For patients that I think should be DNR, I go into graphic detail pretty aggressively that we can do chest compressions which can break ribs and puncture lungs, which can be very painful, and we can put them indefinitely on a machine that could prolong their life without improving their quality of life. Then I usually say, ‘but of course it is your decision and it should be what you think they would want.’” (Hospital A, PGY-3: 11)

“This is kind of paternalistic, but if I feel strongly that the patient wouldn't benefit from resuscitation, I'll be pretty graphic...’Do you want the doctors to go in and press on the chest to pump blood through the heart?’ I want you to know we have to press really hard and break ribs...Sometimes it doesn't work anyway. So it's pretty physical and can be kind of violent. If you want us to do that, we'll do anything that you want for your grandmother” (Hospital B, PGY-2: 15).

“By default we'll do everything which includes chest compressions, which means someone on top of you compressing your chest and breaking your ribs. Trying to be as non-judgmental as possible in the sense that, but then saying, ‘Especially in an elderly individual who is frail, it will entail breaking your ribs and potentially causing a lot of distress.’ And then electrical shocks and medications to try to get your heart to beat again...they're *really* pushing down...If they're doing it right, you break ribs. There are electric shocks, which people have described as being kicked by a horse, potentially many times...I try to be descriptive about it. If they

still say yes, I want everything to be done, I do probably subscribe to autonomy over beneficence in the sense that...I don't know, maybe I'm jaded too much in the sense that in this hospital I've seen people do so much to themselves...I can't force you to do the right thing" (Hospital B, PGY-3: 13).

Rather than persuading the patient/surrogate that resuscitation would not result in meaningful survival, the physician trainee attempts to manipulate the patient/surrogates' *perception* of the actual choice. While honest descriptions of the resuscitation process are important, these descriptions should be presented to improve understanding, rather than as the *specific* means to dissuade. The appeal to emotion rather than cognition embedded within these graphic descriptions distinguish these manipulative strategies from that of persuasion.

It is interesting to note the respondents' tensions between feeling like they must neutrally offer choice ("Trying to be as non-judgmental as possible" (Hospital B, PGY-3: 13)) and a desire to persuade the decision-maker to pursue the "right" treatment. The emphasis on freedom of choice is clear: "but of course it is your decision and it should be what you think they would want" (Hospital A, PGY-3: 11). They state that they'll "do everything" (Hospital B, PGY-3: 13 and Hospital B, PGY-2: 15) and offer a menu of choices, but the message conveyed is that to choose "everything" involves pain, violence, and harm. Also notable is the tension these trainees feel between respecting autonomy, acting with beneficence, and not being paternalistic. Hospital B, PGY-3: 13, notes after his description that he still subscribed to autonomy over beneficence, while Hospital B, PGY-2: 15 recognised that these descriptions were potentially paternalistic.

This attending physician described some of his concerns with this strategy:

"I won't get into representing how sick you are, but instead say, 'would you like us to pound on your chest and break your ribs.' They are infusing it with such aggressive language that there is a right answer...and it's potentially not an accurate way to frame it...It is so laden with bias that you're taking away the patient's autonomy but still have the illusion of giving full autonomy to them.... There's been an unhealthy over-emphasis on leaving it so much in the patient's court that it has left to crafty workarounds with how the discussion is framed. Using such negative language that patients bristle at the notion of being resuscitated" (Hospital B, Attending: 6).

Experienced physicians and palliative care physician respondents never described themselves as utilizing this strategy of graphic descriptions. Although there was some variation amongst institutions, with attendings at autonomy-focused hospitals palpably more concerned about autonomy than attendings at beneficence-oriented hospitals and the latter more willing to be directive when necessary, overall they had an approach to these conversations that was more focused on discussing and ultimately recommending how treatment would align with the patient's overall goals of care:

"It's a decision that...will evolve out of discussions about goals of care...often [a DNR] is a natural order once you've made certain decisions about what your goals are.... So once you've decided that there's not effective treatment for the cancer,

I'm going to recommend against resuscitation...and almost always patients agree to that...we can respect their choice if someone says "look I'm not ready to give it up yet, Doc." Fine, we're not going to give up until you're ready, but I think we need to recommend. If you can make it a large understanding of what are our goals of care, what are our options and "how would you like to die", "where would you like to be", "what kind of things would you like in place when you die?", then I think resuscitation becomes just part of it." (Hospital B, Attending: 2).

Trainees at beneficence-focused hospitals appeared to straddle the continuum between the more goals of care-oriented conversations that experts and more experienced physicians used and the graphic descriptions of autonomy-focused trainees. Many trainees at these institutions were similar to experienced physicians in that they understood the importance of placing these conversations in the overall context of the patient's goals and values and whether resuscitation would realistically achieve that goal. This strategy promotes autonomy by fulfilling the non-control criteria as well as enhancing understanding of their options in relation to the patient's biography:

"A totally reasonable thing to do is to have a conversation about goals. The true ideal of this is...to have a conversation about what life means to them and [their] goals...and say 'all right, for somebody like you having CPR means you'll have no chance of ever leaving a skilled nursing facility' and you hear somebody say 'that's not life.' Based on that, I think it's the right thing for you" (Hospital C, PGY-3: 10).

"It involves asking them if they've...thought about it before and if they have any thoughts on it. It's just a case of asking them quite openly. By doing that, you also gauge what they understand. That helps you to gauge what they want you to do not just in terms of resuscitation...but in their general treatment" (Hospital D, Junior fellow in Oncology: 15).

When faced with patients who wanted resuscitation despite physician recommendations, more trainees at beneficence-focus hospitals accepted patient preferences even if it conflicted with their recommendation. They allowed autonomy to be honoured by respecting choice while encouraging further discussions to enhance understanding and possible consensus:

"If somebody is telling me that they want to be full code, even if from a medical standpoint I feel like that might be counter to my own belief system of what would be the best care I could provide them as a physician, I will take it at face value until I can sit down and describe what it actually means. Trying to tease out what people's goals are a little bit more." (Hospital C, PGY-2: 13)

"I think if a patient's said, "No, I want to be resuscitated" and you have explained [everything], and they can make decisions...they know that their ribs are going to get broken...and get hypoxic brain injury. But they also know that there is a small chance it could work and they could get better. You need to respect that could happen. For them it might be important to have two weeks...If they know that and they know all the risks and then, yes [I accept that]. But that's also quite unusual." (Hospital D, F2: 16)



However, some trainees described conversations in this way:

“Phrasing it in the context of, ‘do you think your loved one wants to pass peacefully or go through aggressive measures including fractured ribs and invasive procedures would be consistent with their wishes?’ It’s so much in the phrasing in so far as helping the family member to say yes or no to that question” (Hospital C, PGY-3: 11).

“I said, this means she wouldn’t want people pounding on her chest and breathing tubes down her throat and often bloody and gruesome measures at the end of her life. Instead, we can offer her things to make her more comfortable through comfort care that we offer people at the end of their lives” (Hospital C, PGY-3: 12).

These quotations reflect these trainees’ understanding of the importance of goals of care conversations; placing treatment options in the context of the patients’ wishes. However, the use of graphic descriptions in these two quotations illustrates the fine (and debatable) line between manipulation and persuasion. These quotations reflect a blend of elements of goals of care conversations and manipulative language. It is as if they recognize the importance of goals of care conversations but have not yet learned how to avoid manipulative language in its delivery. As such, these trainees appear to facilitate autonomy better than trainees at Hospitals A and B, but not as well as experienced physicians, by increasing patient understanding and decreasing non-control.

## Communication Pathologies from the Perspective of Habermas’ Theory of Communicative Action

Jürgen Habermas’ Theory of Communicative Action provides insights into why these graphic descriptions may be problematic and helps us critique this model of autonomy’s dubious claims to patient empowerment (Habermas, 1984). Habermas builds upon Max Weber’s work on bureaucratization and critiques bureaucracy’s orientation towards reasoning for the purpose of efficiency and control. He describes this rationalization as a means to *instrumentalism*, which seeks to homogenize and formalize human activities, leading to bureaucratic dehumanization (Blaug, 1995).

For Habermas, the instrumental rationality of these bureaucratic social organisations threatens to overpower, or colonise, the *lifeworld*, the contextually derived lived experiences of everyday life (Habermas, 1987). The lifeworld consists of interactions and relationships established through shared cultural understanding and meanings. Through these shared meanings, people are able to interact with and interpret each other based on a mutually understandable set of assumptions.

Lifeworld interactions occur on a more equal footing where *communicative action* prevails (Barry, et al, 2001). Communicative action is oriented towards understanding, where all speakers engage at a mutually open level to reach “an agreement that will provide the basis for a consensual coordination of individually pursued plans of action (Habermas, 1984: 289).” Conversations are jointly constructed, negotiated, and agreed upon: “participants pursue their plans cooperatively on the basis of a shared definition of the situation...the

attainment of consensus can itself become an end...Participants cannot attain their goals if they cannot meet the need for mutual understanding” (Habermas, 1987).

The *system* lies in opposition to the lifeworld, which is epitomised by capitalist markets and its focus on profit with its legal and bureaucratic forms of power. Communication strategies in the system are characterized by *strategic action* that orients speech actions towards success, where the ends are defined by technical success rather than moral objectives. Strategic action “instrumentalises speech acts for purposes that are contingently related to the meaning of what is said” (Habermas, 1984: 289). The system’s use of strategic action is used to maintain its dominance, by using speech not just to say something, but also to achieve a purpose. To summarise, strategic action is used when an actor uses communication to achieve his goals whereas in communicative action the actor uses communication to achieve mutual understanding.

Strategic action can be further partitioned into *open strategic action*, where speakers openly pursue the aim of influencing and *concealed strategic action*, where this attempt at manipulation is hidden (Scambler and Britten, 2001). When strategic action is concealed, the other party cannot participate in the conversation at an equal level, as they are not aware that strategic action is happening. In contrast, in communicative action, both speakers can dialectically engage in the conversation by raising criticisable *validity claims*, which allow both parties to judge whether the communicated facts are truthful, appropriate, justifiable, and/or sincere (Habermas, 1984: Ch 1). Rationality by both parties are used to accept or stand up against speech acts and in the process, establish a dialogue to co-create consensus.

Habermas further partitions concealed strategic action into *conscious deception*, which he describes as manipulation, and *unconscious deception*, or systematically distorted communications. Systematically distorted communication is pathologic because the speaker manipulates and exerts influence through concealed means such as through technical jargon. This deception can be conscious or unconscious, where neither the doctor nor patient are aware that strategic action is being used. The doctor uses systematically distorted communication to act “with an orientation towards success, not understanding, but yet sincerely and in good faith” (Scambler and Britten, 2001). The boundaries between intentional and unintentional action blur. The difference lies with the capacity of the patient to openly engage and reason at an equal level with the doctor, rather than in conscious deception or manipulation where a doctor uses “technical jargon to browbeat, subdue or gain assent from a resistant patient” (Scambler and Britten, 2001).

In *The Discourse of Medicine: Dialectics of Medical Interviews*, Elliot Mishler adapts this concept of system/lifeworld and the dialectical tension between these two forms of rationality to medicine (Mishler, 1984). He describes the medical equivalent to the system as the “voice of medicine”, which uses strategies like jargon, medicalisation of daily life, and decontextualised interactions to maintain dominance and control. This voice of medicine encompasses technical and scientific interests that strip away the context of the “voice of the lifeworld”. He describes his analysis of a series of outpatient consultations, where physicians use the voice of medicine to strategically carry out their own agenda, thus suppressing the

patient's accounts and purpose. This pattern is similar to the colonisation of the lifeworld, where doctors use distorted communication in a success-oriented manner.

Christine Barry, *et al.* further elucidates the tensions between the voice of the lifeworld and the voice of medicine where she describes four communication patterns across 35 outpatient consultations (Barry *et al.*, 2001). *Strictly medicine* communications occur when both doctor and patient use the voice of medicine exclusively, such as in a simple single acute physical concern. *Mutually lifeworld* situations occur when the patient's agenda is voiced and recognised and both the doctor and patient use the voice of the lifeworld; the patient is "recognised as a unique human being" (Barry *et al.*, 2001). The poorest outcomes occur when the patient's voice is ignored (*lifeworld ignored*) or blocked (*lifeworld blocked*).

Consultations that are mutually lifeworld are most similar to Habermas' ideal speech type, where communicative action predominated and speech is "contextually grounded in everyday events where there is an emphasis on working together to reach understanding through negotiation" (Barry *et al.*, 2001). It is in these situations that patients are most empowered to approach the conversation on an equal footing as the physician. Of note, Mishler and Barry's interpretations of Habermas to the medical context appear to include lifeworld *topics*, in addition to lifeworld speech acts, emphasizing the importance of both in clinical interactions.

## Communication Pathologies in End of Life Conversations – Relating Back to the Interview Data

Applying Habermas's theory to the resuscitation conversations described earlier by trainees at autonomy-focused hospitals, we see that their conversations employ strategic action, where action is oriented towards success rather than to understanding. They use the voice of medicine to distort communications to lead patients towards their desired goal. Those graphic descriptions are entirely true. Describing interventions is an important part of an overall conversation that help patients/surrogates determine the best treatment plan. However, these physicians' intent in using these graphic descriptions were not to foster open communications, but rather to manipulate through distortion of information and to viscerally repel them from choosing resuscitation. This manipulative communication appeared to occur more frequently at autonomy-focused hospitals.

It would require further study to know whether physicians intention to manipulate actually results in patients being manipulated. It is, for example, possible that patients/surrogates are able to determine the motivations of physicians' distorted speech and factor that into their decisions. Habermas was primarily interested in intentionality, which presumably results in actual manipulation. One could hypothesize that in instances where doctors employ strategic action, patients/surrogates are more likely to be manipulated.

Respondents in these interviews appeared to have little insight into how these forms of communication might potentially be manipulative. Most respondents were not deliberately instrumentalising language to manipulate. Instead, they are likely participating in unconscious deception. They are not fully aware that they are frame resuscitation in this

manner for the purpose of strategic action, but more likely they have learned these behaviours from role models. However, trainees have also likely learned from experience that this form of communication might potentially yield their desired outcome so there is also an element of conscious deception that encourages them to act in this way.

This act of dominance stems in part from the flawed discourse of patient autonomy and choice. This is supported by the fact that trainees at autonomy-focused hospitals described these graphic conversations more frequently compared to trainees at beneficence-focused hospitals. Because trainees at autonomy-focused hospitals felt uncomfortable making recommendations, but frequently felt that patients/surrogates choose the “wrong” intervention resulting in harmful treatments and futile resuscitation resulting in significant moral distress (Dzeng *et al.*, 2016), they instead framed conversations in deceptive ways to manipulate patients/surrogates into choosing the “correct” treatment. They did not feel at liberty to engage in open communicative action and felt compelled to act strategically.

It is important to note that in palliative care and internal medicine generally, there are established professional best practices that promotes a focus on comfort and minimization of aggressive treatments and resuscitation when death is imminent. What has not been acknowledged by physician respondents, is that physicians necessarily enter the conversation with an agenda of wanting to act in a patient’s best interest. This is more clearly reflected by trainees at autonomy-focused hospitals with their graphic descriptions. However, this agenda is also present in less obvious ways amongst beneficence-focused institutions that promote goals of care conversations. The language used in palliative care parlance often fails to problematize the inherent tensions between clinician best practices and patient preferences or the potential conflicts between patient and family preferences (Kamm, 2017).

For example, palliative care practitioners frequently espouse a commitment to providing “goal-concordant care” (Turnbull and Hartog, 2017), which is defined as care that is consistent with the patient’s goals and values. However, frequently the physicians’ preferences are that that care is one that maximizes quality of life and minimizes non-beneficial treatments. One suspects that the physician would be less satisfied if the patient’s “goal-aligned care” preferences reflected one of aggressive treatments and resuscitation to the very end. For truly open forms of communication to occur that facilitate a more nuanced form of autonomy, discussions should include disclosure of the physician’s interests and clinical preferences against treatments that are non-beneficial.

### **Graphic accounts of resuscitation as a colonisation of death**

The graphic accounts described earlier in the paper reflect strictly medicine and lifeworld blocked communication strategies. The way that conversations are initiated and framed from the start obviates the possibility of engaging with the voice of the lifeworld. The question is framed as a medical question, “In the event your heart were to stop would you want us to restart it.” Given physicians’ inherent power, patients/surrogates frequently are unwilling or unable to redirect the conversation towards the voice of the lifeworld. Colonisation of the lifeworld has turned death into a medical choice. The system has essentially also colonised

death. Death in this instance has been completely decontextualised and removed from the personal and social context (Scambler & Britten, 2001: 55).

In contrast, the focus of conversations by experienced physicians is on goals of care conversations. Palliative care best practices also encourage goals of care conversations, which are situated in a mutually lifeworld context, asking the patient their values, beliefs, and goals, and craft treatment plans that have the best chance of realistically achieving those goals. The doctor uses language to improve understanding, rather than changing the perception of choices. This was also more frequently seen to a degree, amongst trainees at beneficence-focused institutions:

“It’s not just about the medical well-being but it’s the all-around well-being...As medics we tend to put a lot of emphasis on the medical side...but there are other things you need to take into consideration” (Hospital D, Foundation year 2: 16).

This resident noted that learning to incorporate the lifeworld in these discussions was something that improved with experience:

“I tend to think not just about the getting the DNR itself but what that looks like after CPR and putting that more in the context of who they were as a person more often now than I did as an intern or resident” (Hospital C, PGY-6: 8).

Because their hospitals’ culture prioritised beneficence over autonomy, respondents enjoyed greater leeway to pursue conversations that were more broadly focused. These conversations employ a *mutually lifeworld* perspective, which acknowledges the patient as a person situated in their lifeworld. It allows that biography to be the driving force in the discussion and decision. Also inherent in this is an increased trust founded on a mutual understanding of lifeworld perspectives. This resident at Hospital C demonstrates how the lifeworld perspective can be incorporated into these conversations:

“We have our [medical] experience ...but for some people there is a grey zone that lies outside of clinical medicine, which is religious practices or their social and cultural beliefs that do kind of supersede the medicine...I’m not obtuse enough to think that I know more than their belief [and] cultural system...I’ll usually...tease out a little bit more than what I’m getting at face value, which is ‘this would be against our practice’, to understand why to make sure that there’s not some disconnect between understanding of what CPR entails and what their belief is” (Hospital C, PGY-2: 13).

By fostering mutually lifeworld conversations, the physician and patient/surrogate both agree they are on the same side, and are able to proceed with a deliberative process that allows for a dialogical interaction. This attending at Hospital B demonstrates communicative rationality:

“Ask them about their insight into their illness is what they understand about their disease and try and eventually lead them to talk about what they think the short term and what the long term outcomes of the disease is. And in situations where the ultimate decision that’s made is not very discordant with the medical decision-making, that process itself gives you the answer” (Hopkins, Attending: 8).

This respondent focuses on the importance of the process of decision-making, and the importance of hearing the patients' voice and their own understanding of the situation.

Goals of care conversations not only mitigate manipulation, but also enhance understanding through a richer lifeworld lens, thus promoting autonomy in two ways. A more positive culture that enables true autonomy might also be attributed to a more palliative care friendly culture. Indeed, beneficence-focused and palliative care friendly cultures are likely interlinked. An interesting relationship emerged in the interviews between beneficence and a "goals of care" approach, and autonomy and a focus on "getting the DNR", which is much lamented in the palliative care world as a reductionist, checklist strategy (Billings, 2012). One possible reason for this correlation is that if autonomy is believed to merely equal choice, the "correct" action is straightforward and can be simplified to a checklist. This mentality is convenient to operationalise into a busy resident schedule. In contrast, if one employs a beneficence-based approach, there is no single easy action that allows a physician to act ethically with beneficence. It is an inherently nuanced concept, requiring a tailored approach to each individual scenario taking into consideration both the clinical situation and the patient's goals and values.

### Micro-Actions Reflecting Macro-Sociological Changes

We can draw further insight into how these communication patterns developed by reflecting the effects of macro-sociological shifts from paternalism to autonomy described in the introduction onto the micro-interactions between individual actors and between actors and the larger system. Decades ago, it was acceptable and even expected for doctors to act paternalistically. These paternalistic norms allowed for open strategic action. Changes towards autonomous decision-making made this no longer acceptable. However, rather than fostering true autonomous decision-making, communication practices instead shifted towards concealed strategic action, where doctors unconsciously manipulated language in order to achieve their goals.

While these shifts towards autonomy were meant to empower patients, the strategic concealment of communicative purpose has undermined the original intentions of increased autonomy. Rather than truly empowering patients, this concealed action merely drove the acts of domination underground. This might explain why institutions that focused on beneficence rather than autonomy in fact allowed for a more empowered patient experience by providing the space for open communicative action. Moreover, this discourse of autonomy constrains a doctor's responsibility for patient suffering (Salmon and Hall, 2003):

"Sometimes with these end of life decisions, it becomes like [doctors] don't want to take responsibility to make a decision. But now there's a family and so instead of saying: 'This is what we recommend and this is what we will do and if you don't agree, let's talk about it', they instead say, 'What would you like?'" (Hospital B, PGY-1: 16)

"An alternative system which I got to make the decisions would put a lot more responsibility on me and I think that's one thing that is a relief about our system. You never know who is going to pop right back" (Hospital B, PGY-3: 14).

The unintended negative consequence of this sort of autonomy is that it allowed the doctor to withdraw from the responsibility of choice while still maintaining dominance in other ways. Doctors still choose when to give this choice; they do not ask patients which antibiotic they would prefer. They exert considerable control through framing and manipulation of language and conversations. However, despite doctors' relative power, some doctors feel powerless to act in the patient's best interest – neither party feels satisfied or in control.

## The Applications of Habermas to Medicine and a Proposed New Direction

The literature on applications of Habermas' concept of system/lifeworld to medicine reflects the traditional conceptions of professional dominance. For example, Gemma Edwards states that, "the interaction that takes place between the doctor and patient in a consultation should at least strive to be 'communicative' in this manner. The definition of illness and course of treatment should, for example, be negotiated through an open dialogue that is not influenced by the power of medical expertise" (Edwards, 2012: 36).

This view, I suggest is too simplistic and does not reflect the changing nature of physician power. This monochromatic representation of physicians and their dominance does not reflect variations that occur institutionally, geographically, and amongst physicians of varying experience within the same hospital. If we revisit Mishler, the assumption at the time (which was likely more accurate in the 1980s when Mishler was writing) was that the physician was the agent of the voice of medicine. He uses the provocative term, "inhumane," to describe the care that results from these distorted communication patterns.

Modern day prioritisation of patient autonomy has shifted the power balance towards the patient in a disjointed manner where physicians maintain control of many elements of the interaction but are lacking in others. Younger physicians who have been fully inculcated in a dogmatic understanding of autonomy feel dominated by the *system*, enacted through institutional culture and policies. The young doctor is caught between two roles. They act as an agent of the system/voice of medicine with the patient, but is also acted upon by the greater system. Their own lifeworld becomes colonised by the system during the process of medical education, which slowly removes their recognition of the lifeworld perspective during the professionalisation process and indoctrinates them into the system.

One can look to how the medical profession seeks to better itself and the ideals it aspires to as further evidence that critique of the physician profession on DNR decision-making cannot simply be cast as a physician's quest for domination. Clinical best practices, palliative care practitioners, and experienced physicians advocate a patient-centred approach that focuses on a lifeworld approach that employs open communicative rationalities. One study demonstrated that palliative care experts were less verbally dominant in conversations, allowing more time for the patient to speak and fostered more of a partnership in the dialogue (Roter, *et al*, 2012). Most importantly, they gave less biomedical information and focused more on psychosocial and lifestyle discussions. In essence, these experts acknowledged the lifeworld and utilised open communicative patterns.

The intentions of individual physicians are not primarily to dominate or control. Instead, structural factors such as time pressure, lack of space to be reflective about issues of autonomy, interpretations of policies, and policies themselves contribute to this drive towards strategic action and consequent “inhumane” care. Thus, to fully dissect and ameliorate these communication pathologies, we must recognise the way the lifeworlds of young physicians are themselves colonised by the system.

## The Unintended Consequences of Individual Actions Producing the Structure of Wayward Autonomy

Much of the literature on the social transformation of the American physician suggested that physicians were either unaware of or resistant to the necessary power shifts in medicine. For example, McKinlay and Arches described that physicians at that time were unable to fully comprehend the corporatisation that was occurring in their profession (McKinlay and Arches, 1985). They emphasise in subsequent papers that physicians have been increasingly subject to this process, but that it was masked by an “elitist conception of their role, so that even if the process is recognised, doctors are quite reluctant to admit to it” (McKinlay and Stoeckle, 1988).

These claims might reflect physicians’ relative lack of awareness in the 1980–90s, but they may also reflect their functionalist stance, of which Antony Giddens is critical. Giddens argues that “human agents or actors...have, as an inherent aspect of what they do, the capacity to understand what they do while they are doing it...actors know tacitly about how to ‘go on’ in the context of social life without being able to give them direct discursive expression” (Giddens, 1984). Actors are generally able to explain most of what they do, if asked. The issue is that they ordinarily are not asked.

The interviews reported here generally demonstrated that physicians are aware of this change. When asked, the majority of physicians were able to draw links between the changing nature of the physician profession and a culture of choice and autonomy. More experienced physicians were very aware of the changes in the medical profession over their years of practice, and how it affected their practice. For example, this experienced physician said:

“I think that factor of experience or inexperience is overlaid on a historical shift. I was in training when the Karen Ann Quinlan case was decided. Then the Belmont report came out. That was really the origin of the whole field of medical ethics and discussions of end of life care. So this field has grown up around my career. I’ve seen things change from a very physician-centred, paternalistic approach to one which stresses patient involvement” (Hospital B, Attending: 4).

These insights in combination with the macro/micro sociological changes discussed throughout this paper, reflect the unintended consequences of social action, as described by Giddens in his Theory of Structuration (Giddens, 1984). Here, Giddens brings together structure and agency by emphasising the recursive nature of social life via the *duality of structure*, whereby structure is constantly recreated out of the resources that constitute them. Human social activities are “not brought into being by social actors but continually recreated



by them via the very means whereby they express themselves *as* actors. In and through these activities, agents reproduce the conditions that make these activities possible. Human agents display knowledgeability about their surroundings, which feeds back into the recursive ordering of social practices. They are purposeful agents who have a reflexive knowledge of the structures within which they operate and make choices based on this interpretative understanding. However, aggregated social patterns emerge out of these individual human actions. These unintended consequences then constrain choices, imposing a structure or pattern onto human behavior.

Physicians are certainly aware of the social changes in their profession and the resulting prioritisation of autonomy, which they have accepted as a necessary and important component of physician professionalism. The problem is that the pre-existing structural constraints of the hospital such as workflow, limited time, and the hidden curriculum hinder trainees' abilities to develop a nuanced, mature understanding of autonomy. Their interpretation of policies promoting autonomy then become warped into a simplistic notion of choice, sometimes even reflecting a false or forced choice.

While the original intentions of autonomy were positive, the unintended consequences of this autonomy interpreted through individual physicians feed back onto the overall structure to create the pathologic systems of communications I describe in this paper. Power transferred from the doctor to the patient during this professional evolution occurred in a piecemeal manner, resulting in perceived lack of power by physicians but without the commensurate improvements in patient empowerment that American and British society desire.

## **Conclusion: Autonomy, Ideology and Emancipation**

Habermas' theories have always had an emancipatory goal, employing these insights into distorted communication as a means for securing freedom by highlighting people's capacity to reason and make rational decisions (Held, 1980: 317). His interest in knowledge stemmed from his belief that self-reflection, self-understanding, and awareness of forces that influence them, could achieve autonomy and emancipation. He draws inspiration from Sigmund Freud's psychoanalytic therapy where the goals are to change behaviour by shifting "what happens to the individual into what the individual makes happen" (Giddens, 1985: 126).

Habermas believes that the goals of critical theory should be the same, where individuals actively control their own lives through an enhanced understanding of the forces that influence it. With reason and understanding as a central tenet of autonomy, neither the doctor nor patient can withdraw from the responsibility of decision-making, as these acts are not passive and require the dialogical engagement of both parties. By conceptualising challenges in end of life communications through this emancipatory lens, we can focus on the ability of individual actors to truly empower themselves rather than through paying mere lip service to the idea of individual choice and autonomy.

When the lifeworld rather than the system is engaged, ends are defined by moral considerations rather than by technical ones. Awareness and critique of these distorted communication practices allows us to unmask the contradictions of the current rhetoric of patient empowerment which continues to dominate through an illusion of patient autonomy and encourages us to seek a more effective way to transform the physician-patient relationship. Habermas critiques the use of ideology as a controlling mechanism by the system, as a technocratic justification for the current social order. However, this dogmatic adherence to ideology can be delegitimised if they cannot be validated when subjected to rational discourse.

In contrast, Giddens believes that ideology reflects the “capability of the dominant groups or classes to make their own sectional interests appear to others as universal ones. Such capacity is therefore one type of resource involved in domination” (Giddens, 1979). While Habermas emphasises the role of the system in using ideology as a controlling mechanism, Giddens attributes ideological dominance to that of the dominant class (i.e. physicians themselves). Giddens’ Structuration Theory allows us to reconcile and unite these two contrasting theories. The interpreted knowledge and actions of individual physicians feeds back onto the overall system. This recursive social pattern in turn has the unintended effect of constraining both physicians’ and patients’ choices. As such, both the dominant class of physicians and the system recursively act upon each other to produce a controlling effect.

This paper focused on the problems associated with the tendency towards an unreflective ideology of autonomy and choice, especially at autonomy-focused hospitals. Critical theory’s critiques of ideology shed light onto the problems associated with this dogmatic way of thinking; “Their ideology is what prevents agents in the society from correctly perceiving their true situation and real interests; if they are to free themselves from social repression, the agents must rid themselves of ideological illusion” (Geuss, 1981).

The problem with the ideology of autonomy is that it legitimises and stabilises certain kinds of social practices. Physician trainees’ over-interpretation of policies that encourage patient autonomy constrains them to act in ways that cause moral distress, but they feel powerless to act otherwise (Dzeng *et al.*, 2016). Ideology is also something that “masks social contradictions” as seems to be the case in medicine’s ideology of autonomy and patient empowerment (Geuss, 1981). The focus on patient empowerment in modern medicine as a means of honouring autonomy is contradicted by the disempowering elements of systematically distorted communications and lack of understanding of the medical circumstance to make a reasoned decision. Rather than focusing on a flawed ideology of autonomy for autonomy’s sake, Habermas’ Theory of Communicative Action teaches us instead to empower patients by emphasizing the need to co-create consensus through open communications.

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**Table 1:**

Hospital Characteristics and Do-Not-Resuscitate Policies (adapted from Dzeng, 2015). For more detailed descriptions please refer to Dzeng, 2015.

Hospital	Geographic Location	Ethical basis of decision-making	Policy
A	North-East, USA	Autonomy-focused	State policy requires that physicians must obtain consent before entering a DNR order “even if the physician concludes that administration of cardiopulmonary resuscitation would be ‘medically futile.’” (New York State policy) (Spitzer, 2003)
B	Mid-Atlantic, USA	Autonomy-focused	Per hospital policy, DNR orders are implemented with consent of the patient or surrogate. The patient or surrogate must be assured that they have a choice on resuscitation decision free from coercion, and are free to rescind a DNR at any time. Physicians are not obligated to provide medically ineffective treatments, but must provide care until a transferring institution is found.
C	Pacific North-West, USA	Beneficence-focused	Hospital policy states that a DNAR can be written if the patient states a preference for a resuscitation not to be attempted or if the physician believes resuscitation would be futile. The ultimate decision, per hospital policy, lies with the physician, though in most cases this represents a consensus between the physician and the patient/surrogate.
D	East of England, United Kingdom	Beneficence-focused	National UK policy states that DNACPR decisions should be made in the best interest of the patient based on clinical assessment and patient’s wishes. The overall decision for resuscitation status lies with the consultant. The consultant is not obligated to provide treatment that is not clinically appropriate for the patient.(UK General Medical Council, 2010)

**Table 2:**

## Demographic Characteristics of Study Participants

	<b>Hospital A (n=13)</b>	<b>Hospital B (n=16)</b>	<b>Hospital C (n=13)</b>	<b>Hospital D (n=16)</b>
Years of Experience	2–45	1–42	2–40	2–34
Range	12.85	15.5	12.85	14.75
Mean				
Male:Female	6:7	11:5	6:7	11:5
Professional Status				
Attending or Consultant	6 (46%)	9 (56%)	5 (38%)	9 (56%)
Fellow or SpR	3 (23%)	3 (19%)	4 (31%)	4 (25%)
Resident or FY/CMT	4 (31%)	4 (25%)	4 (31%)	3 (19%)
Internal Medicine Subspecialty				
General Internal Medicine	5 (38%)	10 (62%)	5 (38%)	4 (25%)
Pulmonary/Critical Care	6 (46%)	2 (12%)	6 (46%)	4 (25%)
Palliative Care	1 (8%)	2 (12%)	1 (8%)	1 (6%)
Geriatrics	0 (0%)	0 (0%)	0 (0%)	3 (19%)
Oncology	0 (0%)	1 (6%)	1 (8%)	4 (25%)
Cardiology	1 (8%)	1 (6%)	0 (0%)	0 (0%)
Neurology	0 (0%)	0 (0%)	1 (8%)	0 (0%)

SpR: Specialist Registrar; FY: Foundation Year; CMT: Core Medical Training