What Can Words Do? Debating a "Good" Death in French Palliative Care/Le pouvoir des mots: une <> mort en debat dans un service francais de soins palliatifs/O que Podem Fazer as Palavras? Debatendo uma "Boa" Morte nos Cuidados Paliativos Franceses.

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Abstract:
This article explores the ambivalent ways that care providers in a southern French hospital (the Center) thought about patient subjectivities and the power and role of language as they argued about how to orchestrate a "good" death in palliative care. By analyzing the case of Monsieur Rami, a 67-year-old Moroccan-born immigrant who died of metastatic cancer in the summer of 2017, I argue against the presumption that individual autonomy, rational choice, and linguistic transparency are hegemonic in Western Europe, particularly in biomedical domains. Instead, I use the disagreements and frustrations that surrounded Monsieur Rami's last weeks to trace out the variety of conflicting ways that care providers talked about his family entanglements, the role of cognitive knowledge and "choice" in end-of-life care, and the power of language itself. Care providers in the Center certainly sometimes characterized Monsieur Rami as a (potentially) autonomous, choosing individual who required transparent communication about his prognosis and diagnosis. But such characterizations sen/ed as ideological weapons in battles care providers were fighting amongst themselves over their own contradictory ethical commitments. And in palliative care, those competing ethical commitments were often grounded in assumptions about intersubjectivity and irrationality, as well as the performative power of words.

[Keywords: France, palliative care, medical ethics, neoliberalism, language ideologies]

[Mots cles: France, soins palliatifs, bioethique, neoliberalisme, 'language ideologies']

[Palavras-chave: Franca, cuidados paliativos, etica medica, neoiiberalismo, ideologias da linguagem]

[phrase omitted]

Full Text:
In early June of 2017, 67-year-old Monsieur Rami was admitted to a government-funded French Cancer Center (hereafter the Center) for pain and general deterioration. (1) He had last been treated at the Center for metastatic ear, nose, and throat cancer in March 2017, when he was told that there were no more treatment options for his condition. At that point, he and his wife returned to Morocco, their country of origin, to see family members and perhaps--rumor had it--solicit the services of a traditional healer. It was now summer and Ramadan. Heat and exhaustion had driven them both back to southern France and directly to the Center, where Monsieur Rami was being treated for pain and an increasingly crippling cough associated with lung lesions.

Within three weeks, Monsieur Rami was dead and the internal medicine and palliative care teams (2) that had been treating him were in turmoil. In the weeks prior to his death, Monsieur Rami's medical team had--in increasingly frantic ways--described his case as a "problem" that eluded solution. In the end, a number of the doctors and nurses on the palliative care team insisted that Monsieur Rami had died a "bad" death, the kind of death that palliative care was supposed to have eliminated. In the final hours of his life, as his respiratory distress increased, he had stopped taking the analgesics that were palliating his pain; he had also refused to be sedated when he started to suffocate. Many of his nurses and doctors attributed this "bad" death to an endless series of communicative failures that deprived Monsieur Rami of his autonomy and a say in the staging of his own exit from the world. But not everyone agreed. Nadege, Monsieur Rami's primary care physician, the only attending of Maghrebi origin who was involved in the case, and the daughter of a good friend of Madame Rami, was furious with her colleagues. She insisted that her patient had died a "good" death precisely because his autonomous individual desires had been fully realized.

On the face of it, this case sounds simple. It looks like additional proof, if such a thing were necessary, of the triumph of what is often called "neoliberal" governmentality and subjectivities in Europe (Mahmud 2014, Muehlebach 2012, Shoshan 2016, Zigon 2011) and in biomedicine (B. Good 2010; Gordon 1988; Rose 1998, 2007; Drought and Koenig 2002). Although there is tremendous diversity in how scholars talk about neoliberalism (Ganti 2014), here I am referring to the widespread presumption that changes in contemporary capitalism and state practice produce and presuppose individualized, rational, autonomous, self-making subjects who use language in transparently referential ways (Abu El-Haj 2012, Comaroff and Comaroff 2009, Muehlebach 2012, Rose 2007, Rudnyckyj 2009, Shoshan 2016). And indeed, despite deep disagreements, everyone in this story seemed to measure the quality of Monsieur Rami's death against precisely these neoliberal metrics.

But viewing the Rami case as evidence of neoliberal hegemony may be a superficial reading of a more complex reality. By tracing the disagreements and frustrations that accompanied care providers' attempts to orchestrate a "good" death for Monsieur Rami, I show just how unsettled foundational assumptions about subjectivity, personhood, and language actually were among the Center's diverse care providers. Like many terminal patients at the Center, Monsieur Rami was hospitalized in an internal medicine ward under the care of an internist (Nadege), but was also seen by an interdisciplinary team of (mobile) palliative care specialists, including a social worker, psychologist, physical therapist, nutritionist, pain specialist, and nurse. Staff meetings about his case included the oncologists, internists, and nurses from the internal medicine ward as well as a representative team of specialists from palliative care. Across these differences in department, training, and specialization, doctors and nurses did sometimes describe Monsieur Rami as a (potentially) autonomous, choosing individual in need of transparent communication about his prognosis and diagnosis. But such characterizations often served as ideological weapons in battles care providers were fighting amongst themselves over their own contradictory ethical commitments. Furthermore, both inside and outside palliative care, some of those ethical commitments were not about cultivating autonomous choice and self-care. For some care providers, talking about Monsieur Rami in terms of thwarted individual autonomy served as a defense of the paternalistic decision-making required for an appropriately "palliated" death. For Nadege too, the language of individual autonomy was strategic, but she used it in defense of a different project. After trying to convince Monsieur Rami's medical team that he and his family should be allowed to cope as a tightly knit, hierarchical collectivity, she finally got fed up with the nursing staff's racism. At that point, she began invoking a kind of culturally conditioned autonomy in order to justify the Rami family's collective denial and subjective entanglements.

Attending to these ambivalent and inconsistent evocations of individual autonomy pushes back against abstract Foucaultian arguments about neoliberal governmentality and subjectivity in the West (Rose 2007, 1998). It also raises questions about a more subtle ethnographic literature that finds neoliberal hegemony even in contexts where social actors think they are resisting both atomization and autonomous self-mastery. For example, Andrea Muehlebach (2012) argues that Catholics and Communists in Italy inadvertently enact care in ways that justify individual responsibility for collective well-being, and Jarrett Zigon (2011) suggests that the Russian Orthodox Church unintentionally helps intravenous drug users involved in rehabilitation programs embody forms of self-care and responsibility that are most adaptive within neoliberal Russia. French palliative care and its practitioners could be used to tell a similar story. The impetus for the late 1980s institutionalization of French palliative care came primarily from Catholic priests and clinicians who studied with Dame Cicely Saunders, the Anglican founder of Saint Christopher's Hospice in London (Castra 2003), and early advocates of palliative care in France were often Church figures (Verspieren 1984, 1988). Most significantly, institutionalized French palliative care has long been overtly hostile to discourses about autonomy and choice that are commonly used to promote euthanasia and greater individual "mastery" over death (d'Ornellas 2015). It instead promotes a relational and "accompanied" death (Gaille and Horn 2016). But are such discourses about deeply relational forms of human subjectivity and nonindividualized morality merely ideological, ultimately supporting reductive neoliberal hegemonies?

The Rami case suggests otherwise. I show this by attending not only to what caregivers said, but also to the assumptions care providers seemed to make about the very nature of language and what it does. There has been considerable work, both inside and outside medical anthropology, on what Judith Irvine and Susan Gal call "language ideologies," meaning, among other things, cultural presumptions about the ontology of language, including the relationship between words and things-in-the-world (Brada 2013, Briggs 2005, Gal and Irvine 2000, Keane 2007). Around questions of death and dying, scholars have paid particular attention to assumptions about what diagnostic and prognostic words can do to patients (Christakis 1999; Frank et al. 2002; M.-J. Good et al. 1993; M.-J. Good 1990; Gordon and Paci 1997; Harris, Shao, and Sugarman 2003; Livingston 2012). Much of the scholarship in medical anthropology on this subject seems to presume that in places and among people fully penetrated by biomedical norms, cultural assumptions separate language from the world, making it purely referential and informational (Brada 2013:438). In contrast, at the geographical as well as cultural edges of biomedical knowledge, words are thought to shape the material world itself and thus impact health outcomes (Frank et al. 2002;, Gordon and Paci 1997; Harris, Shao, and Sugarman 2003; Livingston 2012). This does not mean that doctors in the North Atlantic are not careful about what they say to patients and how they say it. They are. But even when scholars of North Atlantic medicine pay attention to this, they shy away from linking that care to fundamental assumptions about words and the world (Brada 2013). Instead, this linguistic care is associated with the work of shaping patient "choices" (Drought and Koenig 2002; Kaufman 2002, 2005, 2015), avoiding responsibility for particular outcomes (Christakis 1999), or "preserving hope" against all odds (M.-J. Good 1990). My story complicates this picture. As clinicians worked to orchestrate what they understood as an ethically acceptable death for Monsieur Rami, they tacked back and forth between suggesting that words did, or should, transparently reference things in the world and suggesting that words had material consequences. In a medical context seemingly fully penetrated by biomedical norms and assumptions, doctors and nurses seemed to be operating between at least two different language ideologies--one referential and the other performative--suggesting that the way care providers imagined patient personhood and subjectivity was hardly given or stable.

Palliative Care and the "Crisis" of French Medicine

Monsieur Rami's case could be told as a way of exploring death and dying in French palliative care. For the purposes of this article, however, I focus on one specific aspect of Monsieur Rami's experience: his care providers' impasses and anxieties around ethical action, individual choice, and patient autonomy. But why, then, take palliative care and palliative care providers as an ethnographic object? I did not initially intend to study palliative care. Instead, as France transitions between an openly paternalist approach to medicine toward a greater emphasis on patient rationality, autonomy, and choice, (3) I wondered how doctors working in domains driven by patient requests--notably assisted reproduction--negotiated and imposed ethical limits on patients and practices. As I began doing participant observation with an interdisciplinary hospital ethics committee at a large public hospital in southern France, palliative care nurses and doctors approached me, insisting that they wrestled with ethics and autonomy in ways that others (including ethics committees) did not. I therefore found myself spending about six months attending staff meetings and workshops with three different teams of palliative care nurses and physicians based in publicly financed French hospitals in a medium-sized Mediterranean city. While shadowing the nurses and physicians working in and around palliative care, I did not observe patients (like Monsieur Rami) or staff relationships with patients; instead, I focused on how care providers trained interns, why and when they argued with one another, and how and why they struggled to shape the ways that staff in other medical domains thought about and handled patients.

In retrospect, it is not surprising that palliative care providers perceived themselves as deeply engaged with ethics and autonomy. Palliative care in France emerged as a reaction against the fantasies of physician omnipotence that produced both "archarnement therapeutique"--the endless deployment of technology in hopeless cases--and/or physician-driven euthanasia performed with so-called "lithic cocktails" (Carnevale and Bibeau 2007, Castra 2003, Moulin 2000). In interviews, palliative care providers consistently defined themselves in opposition to what they called the French physicians' "God complex" and stressed their own contrasting anti-paternalistic, patient-centered approach to care. Although antipaternalism does not have to rely on liberal notions of autonomy, many palliative care providers talked about their work and their patients in ways that emphasized rights-bearing, internalized selves. They insisted that they were safeguarding patients' "rights" to minimal pain and robust pain management, as well as the "right" to limit unwanted "heroic" medical measures (Salamagne and Thominet 2015). In addition, care providers described patients as having a conflicted but interiorized self that required carefully curated opportunities for self-realization and self-expression. This was particularly true for the psychologists involved in palliative care, who encouraged patients to share (and preferably narrate) their life projects, fears, and desires (Castra 2003; Memmi 2000, 2003). Encouraging this kind of self-presentation presumes that language can, first and foremost, "align presumed interior states and external self-representations" (Brada 2013:441). And since talk was supposed to reveal and make accessible what was always already occurring deep within patient psyches, inciting this kind of self-presentation both assumed and helped produce patients who were self-reflexive and in possession of deeply individualized inferiorities.

And yet if palliative care providers seemed to embrace the self-reflexive, sovereign subject as a way of pushing back against the "bad old days" of paternalism, many also distrusted biomedical understandings of individuality and autonomy. This distrust was perhaps overdetermined by palliative care's long-standing fight with the French "right to die" movement, which makes its moral claims through arguments about furthering patient "autonomy" (Salamagne 2015, Zittoun 2015). Laure, the head of palliative care at the Center, explained that she was wary of the "excessive individualism" she saw in shifts towards global norms around "consent" and "autonomy." She feared this individualism would allow people to make their own rules and ignore shared moral frameworks, undermining the foundation of what makes people "human." She also did not like the idea of leveling hierarchies between doctors and patients because such leveling rested on the illusion that a patient could autonomously "choose" among treatment options if given complete and transparent information. Paul, a former colleague of Laure's who was working in a different palliative care center, agreed with the idea that autonomous choice in critical medical care is chimerical. He summed up his moral position as "ethical paternalism": "I don't like a fully hierarchical relationship with patients. But I don't like the autonomy thing either. I have knowledge that I am willing to put into service through discussion and sharing. But I am not responsive to the 'demands' of patients." As Laure and Paul suggested, many palliative care doctors imagined themselves as fighting both paternalism and bioethics models of human subjectivity. Such models made doctors mere service providers who were judged by their responsiveness to putatively transparent patient demands. Accepting such demands at face value opened the door to an "anything goes" morality; it also transformed doctor-patient relations into a series of (more or less transparent) communicative acts focused on facilitating patient "choice" (Mol 2008).

These tensions between anti-paternalistic, patient-centered norms, on the one hand, and hostility toward patient demands and choice-driven autonomy, on the other, have existed within French palliative care from its genesis in the mid-1980s. But they became more pronounced right before my arrival in the field in January 2017. In 2016, the French parliament revised the 2005 loi Leonetti governing end-of-life care (Leonetti 2005). The 2005 law was well-regarded by palliative care specialists because it walked a tightrope between patient autonomy and allocating moral and decisional responsibility to doctors. It encouraged patients to write advance directives, but made it easy for physicians to ignore them. It facilitated treatment refusal for dying patients, but required doctors to talk people with longer life expectancies out of such refusals. And it formally authorized a long-standing physician practice of using potentially fatal sedatives on patients as long as the medical intent was to temporarily palliate refractory symptoms, not to kill (Leonetti 2005, Verspieren 2005). The 2016 law, in contrast, went much further toward "choice" and "autonomy," partially fulfilling then socialist President Frangois Hollande's 2012 campaign pledge to give French patients more control over their own deaths (Hirsch 2014:19-20). Much to the dismay of many of the care providers I got to know, the 2016 law allowed dying patients to request sedations that were intended (in the long run) to be terminal. Fragile patients had often died while temporarily sedated; but this was seen as very different from a patient insisting at the outset that he or she did not want to wake up. The new law also made it harder for physicians to contest or ignore advance directives (Claeys and Leonetti 2016).

All of these shifts and debates made palliative care particularly fertile ground for exploring wider tensions within French medicine around ethics, autonomy, and language ideologies. In this context, palliative care specialists from a range of religious and spiritual backgrounds had become particularly attuned to and even defensive about their own ambivalence around patient autonomy. In conversations with me, they mobilized arguments about autonomy seemingly to beat the autonomists, particularly those seen as defenders of euthanasia. (4) For example, Genevieve, a pioneer of palliative care and a lapsed Protestant, told me that people who requested terminal sedation were not actually asking to be killed. Instead, their "real" desires had been silenced by pain, isolation, or psychological distress. If palliative care specialists responded to the suffering at the root of the request for euthanasia, the request itself would disappear. Similarly, Laure, who described herself as an atheist humanist, explained that patients were asking to be terminally sedated because they worried about being a financial and emotional burden for family members. Rather than understand this as a manifestation of distributed suffering (Hannig 2017), Laure saw fears of external disapproval--as well as actual familial pressures--deforming patients' true internal wishes. And Paul, a left-wing Catholic, was convinced that euthanasia was the government's solution to out-of-control medical spending. In Paul's account, powerful economic forces disciplined individual desires in a direction he called "au low cost" a phrase that when pronounced in French is identical to the French word for Holocaust. Palliative care doctors were fighting fire with fire, using autonomy as a conscious ideological weapon against the growing echoes of the "right to death" or "death with dignity" arguments in the French public sphere.

The pressure from a rising "right to die" movement may have overdetermined palliative care doctors' situational embrace of Kantian conceptions of autonomy, leading them to dismiss requests that bore traces of external influence or pressure (Laidlaw 2013:164-165). But it also increased the pressure to show that patients died well in palliative care. This pressure created its own ethical complexities, particularly when a painless death was not a patient/family's primary objective. Many of the situations that care providers described as ethically complex involved patients who refused to be temporarily sedated despite symptoms (particularly respiratory distress) that caregivers thought were unbearable. (5) Many providers therefore talked about palliative care as a kind of "choose your own adventure," where patients got to call the shots and nurses and doctors worked hard to facilitate the self-realization of the dying. But physician-recommended temporary sedation was fast becoming an ethical norm for a "good" death.

The Problem of Language in Caring for Monsieur Rami

As is clear from these long-standing moral and philosophical impasses around dying well in palliative care, the Rami case did not create the tensions caregivers experienced or the language in which they expressed those tensions. The case was, in the words of a palliative care psychologist at the Center, "banal" in the sense that it raised very typical ethical dilemmas for care providers. But it raised those issues in particularly dramatic ways. From the very beginning, care providers worried about language and its role in making the Rami case complicated. In staff meetings, doctors, nurses, and aids gave confused and contradictory accounts about Monsieur and Madame Rami's (in)ability to understand/communicate in French and/or Arabic. Different doctors and nurses seemed to see very different realities in the Berber-speaking Rami family, and most particularly in Madame Rami. (6) Sometimes even the same care provider saw different realities at different times. Nadege, for example, at times worried about Monsieur and Madame Rami's limited French and at other times insisted that both were capable of understanding and even speaking French. Natasha, the ward's only Arabic-speaking nurse who translated for the family whenever she could, offered similar assessments of the couple's Arabic. She insisted in staff meetings that Madame Rami "understands [her] very well" in Arabic while also worrying that her Arabic translations were not enough because it was still a second language for the family. For other care providers, the Ramis were incompetent in French and therefore linguistically and culturally inaccessible.

Those who found the Ramis incompetent cited the everyday ways that Madame Rami cared for her husband as evidence. According to the nurses responsible for Monsieur Rami, his wife woke him up to feed him, touched him constantly to see if he was warm, and prevented him from dozing off. She and her children asked for help from the staff constantly. As Eurydice, the head nurse on the ward, explained: "They [the family] say--he's tired! Do something! He's hot! Do something!" They even asked for additional chemotherapy while talking about alternative therapies, including a "fruit that cures cancer." Care providers worried that these comments pointed to the family's informational deficit about Monsieur Rami's condition, suggesting that there were problems with translation and/or transparency in communication. Anne-Marie, a very experienced palliative care nurse, returned repeatedly in staff meetings to the trope of "impasse," insisting that the team needed to find a way to "inform" the patient and his wife of his dire prognosis in order to "get things moving" toward greater acknowledgment of decline and death. This push to get patients and their families "moving" toward articulating recognition of impending death is central to the socio-psychological work associated with palliative care on both sides of the Atlantic. This work assumes and helps create transparent and referential language among medical professionals about disease progression and prognosis and, most crucially in this context, among patients pushed to externalize putatively internal transformations and states.

But at the beginning of Monsieur Rami's stay, care providers also sometimes undermined the very notion that the Rami "impasse" was a problem of thwarted communication. Nadege, Monsieur Rami's internist and primary care physician, tried to explain to her colleagues that putatively transparent communication about illness was not the only way of "knowing" (Samuels 2019). She noted that while the Rami family certainly did not talk to Monsieur Rami about his disease, he nonetheless "knew" what was happening: "He knows that he feels something; he knows that he's exhausted." Similarly, while Eurydice worried openly about how to make sure that the family understood Monsieur Rami's diagnosis and prognosis, she also suggested other ways of interpreting their behavior--notably through the register of denial and even the subjunctive possibility of cure (Good and Good 1994). Defying the open scorn around the "cancer curing fruit," Eurydice, riffing on the theme of Muhammad and the mountain, (7) responded: "He can't go to the fruit but maybe the fruit can come to him ... We need to respect his beliefs. We don't want him to think that we are hermetic. Let's give him the fruit. I'm only sometimes a Cartesian." For Eurydice, "communication" at that moment was not about denotation, let alone the facilitation of rational and autonomous choice. Rather language was perhaps better understood in a more ritualistic sense--as part of the work of creating an "as if" frame in which the family could live the end of Monsieur Rami's life on their own terms (Seligman et al. 2008). If that meant endlessly deferring transparent and referential communication about the patient's impending death, so be it.

In these exchanges, care providers seemed to echo Annemarie Mol's (2008) distinction between "care" and "choice." In a "logic of care" frame, doctors collaborate in open-ended ways with patients who are struggling to live with and in bodies that may be very difficult to control and impossible to cure. In contrast, the "logic of choice" sets up limited, transactional relations that are teleologically focused on autonomous decision-making. Allowing patients and their families to live with disease rather than simply facilitating end-of-life "choices" was certainly how palliative caregivers typically talked about their role vis-a-vis dying patients. I would further suggest that this commitment to life with disease came with all sorts of assumptions about what language is and how patient subjectivities work. Here, I want to highlight a few discussions among care providers that illustrate these entanglements. During a hospital ethics subcommittee meeting, Laure led an hour-long discussion about how to talk to patients about palliative care. What words could they use? Did "accompanying services" (soins d'accompaniement) work? What about "comfort services" (soins de comfort)'? Did terms like these conceal the truth? Were euphemisms necessary? Michele, a psychologist and at the time a member of France's national ethics committee, responded: "Saying things [dire des choses] is not necessarily about Truth--it's a truth. You are not really lying when you do not say palliative care." Laure responded: "There is this terrible Anglo-Saxon idea of [linguistic] 'transparency.' I see it all the time because my boss trained in Quebec and Boston." Michele noted that they have long learned not just to change the words they use with children, but also the tone and rhythm of their speech, noting that doctors should do the same thing for "patients to whom they are announcing a catastrophe. It's not hypocrisy--we do things with words."

Michele and Laure worried that the term "palliative care" could "do things" in an Austinian sense (Austin 1975) because they-and many others in palliative care--thought talking about prognoses or diagnoses with patients was a potentially dangerous performative act. During a medical school class devoted to palliative care, Genevieve--the lapsed Protestant and key figure in French palliative care--explained this to her third-year medical students:

> We cannot live in death. It is unthinkable. There are times when questions [about the end of life] will be asked, but then [the patient] is going to talk about going on a trip to Tahiti; they've never been and now is the time to go. So death is not simple. And you cannot worry if you have informed the patient and then the patient seems to do an about face and starts talking about a life project. To live, you need a project. It might be Tahiti or just next weekend. But you need to keep that door open. You can tell them what you have to say; but then you leave the door open.

A student then asked: "Should we make people understand that they are a lost cause? Or should we do everything we can to make them hang on?" Genevieve responded:

> We never make an annonce [diagnosis and/or prognosis] like that. When people ask, we do not really know what they are asking. Sometimes people ask if they are going to die. So you should say: why do ask that? And then they say, because I do not feel well. So then we say: yes the situation is serious [grave] but we are going to do everything we can. Not to mean that we are going to heal you. That isn't true. But just to leave the door open ...

Regardless of what the student thought before or after this exchange, her question and Genevieve's answer sutured a patient's ability to "hang on" to the physician's relative silence around diagnosis and prognosis. Viewing both words and silences as consequential acts meant that doctors were always looking for the "right" moment to break bad diagnostic news. And palliative care doctors fully acknowledged that such a moment sometimes never came. This suggests that patients were not imagined as autonomous agents making independent decisions through referential language, but rather as subjects roiled with contradictory, even irrational psychological impulses and caught in powerful webs of words and relations that might save or harm them.

But as care providers became increasingly anxious about Madame Rami's "inappropriate" behavior and her seeming ignorance of her husband's condition, the space for "care" and its associated language ideologies diminished and the emphasis on "choice," with its assumptions about patient autonomy, cognitive knowledge, and rational decision-making increased. At the same time, Nadege's role seemed to shift. From having been a reporter on the family's "cultural" issues who sounded much like Eurydice or other members of the palliative care team, she became what her colleagues called an "obstacle" to progress. In particular, Anne-Marie, the senior palliative care nurse who worried about the "impasse" with the Ramis, later blamed Nadege for making "everything seem impossible." And indeed, Nadege found herself saying no to her colleagues quite often in the following weeks. When Eurydice first suggested getting the whole family together in order to finally dispel any doubts about Monsieur Rami's diagnosis and prognosis, Nadege simply ignored the proposition. She changed the subject, commenting that Monsieur Rami's youngest son had just become his healthcare proxy. She said the young man, who spoke fluent French, would not be able to "fully assume his responsibilities" because of his junior position within the family. When Anne-Marie rearticulated Eurydice's proposition a week later, Nadege objected strenuously and vociferously, arms folded stubbornly across her chest. "No! There is a daughter who is psychologically fragile. And culturally, they cannot understand making a diagnosis and prognosis in front of the patient and not just to the family in the hallway." Nadege added that the family was pudique, meaning reluctant to share intimate information. This would make it hard for them to talk about Monsieur Rami's impending death, let alone help the doctors break the news to the patient himself. Echoing her previous concerns about Monsieur Rami's healthcare proxy, Nadege explained that the youngest son could not "inform" his mother. Although he apparently found his mother's behavior problematic and sympathized with the concerns of the medical team, he was too junior a family member to criticize her or tell her about Monsieur Rami's impending death.

In contrast, Nadege's colleagues started to dig in their heels around the necessity of transparent communication. If the week before Eurydice had been happy to facilitate procuring a cancer-curing fruit, things had now changed. And she was hardly alone in her insistence on "better" communication with the Ramis. In one particularly heated staff meeting, AnneMarie, Eurydice, and a nurse from internal medicine unsuccessfully tried to convince Nadege and Natasha, the team's only Arabic-speaking nurse, that referential language was both the cause of and solution to the Ramis' problems (8):

Anne-Marie: Has anyone told her that her husband is going to die? Nadege: We've told her kids, but not her. There's the language problem.

Anne-Marie: We need to move forward here. Why would she not continue to stimulate him [since she doesn't know that he's going to die]?

Internal medicine nurse: Maybe she doesn't know not to stimulate him?

Nadege: There's no communication in the family.

Internal medicine nurse: His wife answers questions on his behalf. His children and friends read the Qur'an. They are not talking to exchange information. They are just getting ready for the benediction chant. It's an obligation because it's Ramadan.

Natasha: Not at all! They are reading to him because he's sick. It's just for him, the benediction. And they are not interested in seeing an imam to share anything.

Nadege: He doesn't say what he wants. He asks no questions. He just says that he is tired. I tell him that there is no medicine for the sickness; [I told him] that it will just keep growing ... The darker son was the first to ask how long this will last; I won't be able to get a dialogue going in this family.

Anne-Marie to Nadege: What do you need to help take care of him? Do you need us [the palliative care team] to deal with the wife who stimulates him too much?

Internal medicine nurse: You need someone to translate for you. The wife will say "yes" [to whatever you say]. But then afterwards [she will do whatever she wants] ...

Anne-Marie: [frustrated with the nurse's fatalism] But we haven't tried! What happens if he dies? Her reaction is important!

Natasha: If he dies, I'm not really sure that there will be a problem.

Eurydice: [furious] Well then! We might as well just wait until he dies!

Natasha: Karima [name of another nurse] speaks to them too. She speaks Berber, and I do not. The wife asks about another patient whom they have known for a long time--the families exchange a lot. [The implication being that a member of this other family could "break" the news to the Rami family.]

Eurydice: [even more furious] NO! We are talking about a woman who is behaving in a totally inappropriate way for the situation. I don't know if it will help to tell her, but we have to try!

There is quite a bit going on in this exchange, perhaps including the interactional creation of anger and anxiety (Capps and Ochs 1995). But here I want to focus on the way language ideologies divide Nadege and Natasha from their colleagues. Nadege--a tiny powerhouse glowering at her colleagues with her arms crossed and lips pursed--seemed to encourage everyone to renounce a model of consent and care in which patients were responsible for cognitively knowing and individually acting on a diagnosis or prognosis. She had told Monsieur Rami that his condition would only get worse. But she had given his children considerably more information about their father's prognosis, knowing full well that they would keep that information from their father and mother to protect them from hearing words that might cause lasting harm. This is why Nadege insisted that there was never going to be a "dialogue" in the family and blocked her colleagues' attempts to orchestrate family-wide disclosure. Through her stubborn opposition, she was reminding her colleagues of something many of them already knew and yet seemed to have forgotten: agency and perhaps even autonomy can be "distributed" as well as individual, particularly when patients' lives and ethical sensibilities are inseparable from those of the friends and/or family who care for them (Fainzang 2016, Livingston 2012).

Natasha, the Arabic-speaking nurse, took this even further. Nadege was convinced that the family was not "communicating" and would never engage in a "dialogue" because they were committed to distributed agency. Natasha insisted that they were communicating, but not in a referential way. This is most obvious in her response to the internal medicine nurse, who denounced the Rami family's use of Quranic readings as a retreat from real dialogue ("they are not talking to exchange information"). In the context of a hyper-secular French hospital, this comment suggested that religious speech was empty, all form and no content, and therefore useless as a form of exchange (Asad 2003, Seligman et al. 2008). But Natasha offered a different account of how language might work. She suggested that the Ramis' textual citation practices were neither empty words nor a sign of a fanatical commitment to Islam ("they are not interested in seeing the imam"). Instead, text and prayer facilitated meaningful and culturally comfortable interactions with Monsieur Rami ("it's just for him, the benediction") (Keane 2007). Contrary even to Nadege, Natasha thought the Ramis were engaged in an exchange that was perfectly appropriate in a certain kind of Muslim family. As a result, she questioned the whole premise of the team's anxiety around Monsieur Rami: there was not going to be a "break-down" or "crisis" when he died. Instead, he, his wife, and his family members were coping with impending death by engaging in ritualized everyday routines that were a kind of subjunctive denial of death (Good and Good 1994, Samuels 2018).

But these openings toward alternative understandings of language were being countered by arguments that made very different assumptions. In the exchange cited above, Anne-Marie and Eurydice insisted in different ways on communicative transparency, making it the path to the knowledge they now suggested was an important component of a "good" death. Back-grounding palliative care's commitment to life with disease in the face of the Rami family's social and cultural dynamics, both claimed that Madame Rami's ignorance--not her denial--enabled her "totally inappropriate" care of her husband. She was "stimulating" him because she had a misplaced hope that oriented her toward an impossible distant rather than more realistic short-term future. This could--both nurses hoped--be corrected with better information coming from the proper channels: Center care providers, not fellow patients. For Anne-Marie and Eurydice, Madame Rami's behavior could best be understood as a transparent reflection of choices driven by (deficient) knowledge; the question was simply which cultural tools would allow efficient communication with the patient and his wife. At the same time, there was growing hostility towards Nadege's attempt to maintain the status quo. Both Eurydice and Anne-Marie raised their voices and offered catastrophic scenarios ("What if he dies!"; "Well then we might as well just wait until he dies!") in the hopes of getting Nadege on board with their plan and its attendant semiotic assumptions.

Autonomy Denied and Realized?

By the following staff meeting, Monsieur Rami had died under conditions that challenged the personal and professional ethics of those who had long been debating his family dynamics. In a staff meeting dedicated to making sense of what happened with his case, Laure gave a blow-byblow of the hours preceding his death. On a Friday, a few short weeks after his initial hospitalization, Monsieur Rami entered serious respiratory distress. According to Laure,

> ... there was this sudden realization in this Muslim family of his impending death, the death of a father and a husband. Frangoise [the ward's on-call oncologist] told them he was going to die and this closed them off completely. She did it rather brutally, perhaps because she was taken aback and extremely frustrated by the way this entire family united in the room with this man challenged her power. And what happened was that the femme agee [Madame Rami] asked us to stop all medical treatment--she wanted us to pull back, to stop pain medication because he was now in the hands of Allah. I tried to push her to the end of her logic, to see exactly where she was willing to stop. But her position was incoherent and her children tried to protect her, saying that it was way too much for her right now to deal with the impending death that had just been announced and the additional medical treatments. She didn't even want him to have morphine, although he had long been on it.

For Laure, the situation was untenable. She noted with horror that the family "even asked a social worker to organize his [Monsieur Rami's] rapatriement [return to his country of origin] while he was lying there gasping for air." A nurse, explaining the anger and frustration of the medical staff witnessing Monsieur Rami's distress, chimed in: "The staff felt like the situation was just going to explode if it kept going."

But Laure also made clear that she had no intention of letting the situation continue. She was convinced that Madame Rami had made a decision that did not reflect her husband's interests or will. Laure explained:

> Our plan was not to let him suffer in the long run. We were going to give the wife some time; we were going to respect her point of view. And we hoped that once she realized that we had respected her, she would start to respect us and follow our advice. In the end that was not what happened; but that is because he died so quickly.

What Laure meant was that after respecting Madame Rami's "point of view" for a few hours, the palliative care team fully intended to medicate, if not "temporarily" sedate, Monsieur Rami. No one at the meeting thought this a shocking proposition, despite the family's obvious opposition. For palliative care providers, dying fully conscious of respiratory distress was both undesirable and undesired. From the team's perspective, it was simply inconceivable that Madame Rami's refusal of additional analgesics was part of a collective strategy for, once again, living with Monsieur Rami's disease until death. The family's violation of one kind of palliative care norm through the refusal of analgesics authorized care providers' violation of another norm: their commitment to simply "accompany" patients.

Given Laure's decision to frame her discomfort with unpalliated death in terms of autonomy, it is not surprising that the post-mortem conversation hinged on the "logic of choice." Notably, the team rehashed the missed communicative opportunities that many thought had plagued the relationship between the Rami family and staff from the very beginning. AnneMarie suggested that they had missed an opportunity to work on the "spiritual" side of Monsieur Rami and his family. Laure agreed, lamenting the lack of communication with the family and the failure to create trust during Monsieur Rami's hospitalization. For Laure and others, such communication and trust might have allowed the patient and his family to cheminent (move, literally go down the path) toward acceptance of Monsieur Rami's condition and impending death. This, in turn, might have prevented both the surprise and distrust that Laure and Anne-Marie thought had led to an unsedated death. It is important to note, however, that despite her frustration with these communication "failures," Laure also almost immediately raised questions about whether fully transparent referential communication was ever possible. She cautioned everyone about assuming that the Ramis' "culture" or "religion" had created a communication problem. For Laure, Madame Rami's distressed "inch'allah" as she negotiated her husband's agony and the team's search to communicate through what they called "religion" and/or "spirituality" were short cuts, part of the "poverty of discourse" in the face of suffering. Words, she seemed to hint, were not, and maybe could not be, simple vehicles of meaning.

Laure and most of the palliative care team were focused on the communicative failures that supposedly prevented the Rami family from "knowing" Monsieur Rami was going to die. But Nadege, who was not present at the palliative care post-mortem, had a very different take. As Sarah, a senior palliative care nurse, explained during the palliative care postmortem meeting, Nadege thought the relationship between the Ramis and the Center was tainted by racism. When I spoke to Nadege a few weeks later, she elaborated, noting that she had overheard nurses referring to Monsieur Rami and his family with the inanimate, gender neutral, indexical pronoun ga, as in ga mange (the equivalent of "that thing eats"); nurses had also locked the family room and the bathroom on the floor in order to avoid, as Nadege put it, seeing "those people with their tetes [phenotypical features], with their veils, with their evening meals." By the end of Monsieur Rami's life, Nadege had become fully aware of the nurses' discomfort and even disgust with the Rami family--a discomfort and disgust that she attributed to anti-immigrant and notably anti-Muslim sentiment.

In response to what she called her "discovery" of racism at the Center and her long-standing opposition to the team's problematization of the case, Nadege changed arguments. Before Monsieur Rami's death, Nadege invoked "cultural difference" in order to make arguments about how the team should care for him. These arguments presumed an irrational, reality-denying self, as well as the performative possibilities of language. After his death, she minimized her discussion of cultural difference and maximized her focus on rational, interiorized autonomy. In other words, she furiously countered both the racism at the Center and the move away from "care" and towards "choice" with her own account of Monsieur Rami's similarity to other patients and his mastery of his own death.

In a long interview a few weeks after Monsieur Rami's death, she dismissed the concerns about language comprehension:

> With this patient ... there was no team investment. Since there was the language barrier, they did not even try to communicate. But ... we have a patient of Polish origin, from Eastern Europe, and they [the nurses] managed to communicate [with him] in other ways. [Monsieur Rami] had an accent that made things difficult; but [he] spoke French. Yes, he spoke French. And his wife, she understood; she could speak French. But you needed to give her room to speak [prendre la parole] in French.

Nadege also insisted that when Monsieur Rami had died, he and his wife knew full well what was happening. Despite rumors at the Center, he had not sought out "traditional treatment," meaning he had never questioned the rationale or efficacy of biomedicine. And

Nadege insisted that she "didn't do anything differently [with him] than with other [patients]." She had told him about his disease, how it would get worse, and that there was nothing that could be done to stop his decline. In this story, Nadege assumed that Monsieur Rami was a patient just like any other. But rather than acknowledge that doctors needed to wrestle with what words might do to all patients, Nadege emphasized her purely referential language-use with Monsieur Rami: she gave him the knowledge required to operate in an individualized, consent-based framework. As a result, Nadege strongly contested Laure's account of Monsieur Rami's death. If Laure thought that Monsieur Rami and his family were "first discovering that this was a critical situation," Nadege insisted that he had long known exactly what was going on. That was why he went to Morocco in the first place--not for the miracle cure his wife might have wanted for him, but because "he knew there were no more treatment options for him." Furthermore, he individually and autonomously orchestrated his death. She explained:

> I didn't have any trouble [telling him that he was going to die] because the family was observant and put themselves in the hands of God ... I tried to be as honest as possible. But uh ... Voila, these are people who clearly have their faith [....] and who uh accepted what I could not do.

Nadege added that although:

> [T]he [medical] team constantly criticized the family for stimulating him, turning him ... he wanted this. Each time he asked his family fora little water; he asked for a spoonful of yogurt; so as long as he could be in contact and in an exchange with them, he asked for things.

Nadege reinterpreted the care her colleagues viewed as "inappropriate" and ignorant as a reflection of Monsieur Rami's conscious and autonomous desire. She explained his medical decisions in similar terms, as the work of autonomous and informed reflection. On the Monday before he died, she saw him to clarify where things stood. She had already told Monsieur Rami's family that he would increasingly feel like he was suffocating. She also explained the pharmaceutical options for coping with these symptoms. The family refused everything. Nadege explained: "There is an expression in Arabic--we die the way we are born," which means that "life" arrives and finishes unfolding "naturally."

> And then I also talked about it with [Monsieur Rami], It was his decision. And I explained that if he wanted to be sedated, even if his family was against it, I needed to respond to his request. What happened was not what I expected. So what he said was: "Yes, I would like to sleep. But what time are you going to wake me up?" And his son did the translation to make sure that he understood that if he were sedated, he would not wake up again. He pulled together all of his energy in order to say to me: "NO, I do not want to be sedated." It was incredible. It was a categorical refusal. There was no doubt. There was no influence. So [sedation] was unimaginable.

In Nadege's post-facto reading, Monsieur Rami's will was fully realized. It was a "cultured" will that could not be separated either from his religious dispositions or from his family's close involvement in both his illness and death. Given all of this, it was hardly surprising that his family refused medication and sedation in Monsieur Rami's last hours. And according to Nadege, this refusal allowed Monsieur Rami to continue to realize his own desires, doing things that would have been impossible had he been sedated. "This was important to respect in the last hours--despite the distress it caused his medical team. He could exchange with his family, he could exchange with the imam; he could realize his last actions so that he could die religiously and culturally in good terms ... that was his will." After Monsieur Rami's death, members of the Rami family did indeed thank the palliative care staff for the care their father had received.

Conclusion

In the end, Nadege and Laure came to diametrically opposed conclusions about the quality of Monsieur Rami's death while nonetheless seeming to agree that a "good" death requires both cognitive knowledge and autonomous individual control over end-of-life "choices." Or did they? Clearly, both Laure and Nadege mobilized an ideology of linguistic transparency, individual autonomy, and choice in their attempts to manage colleagues and the Rami family. But these ideological statements were in the service of care providers' sometimes internally contradictory ethical projects, none of which consistently assumed the possibility or desirability of patient autonomy. As we have seen, Monsieur Rami's medical team was caught between the competing ethical demands of palliative care itself. Although initially committed to allowing the Rami family to accompany their father/husband in their own way, that commitment ran up against ultimately greater commitments to: 1) cheminement, the requirement that a patient and his or her family make "progress" towards acknowledging/ narrating looming demise, and 2) palliated suffering. Privileging these ethical commitments required invoking models of personhood and language that departed dramatically from a framework of "care" with its presumptions about death-defying "denial" and performative (and perhaps even deadly) language (Favret-Saada 1980). Faced with a Maghrebi family whose practices many care providers found troubling, they instead used the language of information deficit and thwarted autonomy to justify proposing robust, paternalistic interventions, including forcing the family to listen to a prognosis and offering unwanted sedation at the very end of Monsieur Rami's life. Similarly, Nadege used the language of realized autonomy to further her own project of protecting the Rami family from the racist views of her colleagues. Nadege may have begun the Rami case presuming both "distributed agency" and linguistic performativity. But in order to maintain such a position in the face of her colleagues' cultural and racial stereotypes, she began insisting that Monsieur Rami had cognitive knowledge of his own prognosis and had individually and autonomously articulated his end-of-life desires. In other words, she defended a certain modality of caring collectively for a patient with a language of autonomy that defied the racialized assumptions of her colleagues.

The conscious invocation of knowledge, choice, and autonomy in defense of care providers' ethical projects may encourage anthropologists to rethink how hegemonic neoliberal assumptions about personhood and language are in some fully biomedical settings, even in Western Europe. Medical anthropologists, including Sharon Kaufman (1997, 2005, 2015) and Barbara Koenig (Drought and Koenig 1996, 2002), have long told us that "choice" is not what is actually happening even in North Atlantic patient care, particularly in highly medicalized settings. But in these contexts, doctors seem to remain deeply committed to a "logic of choice" even when most medical "choices" are in fact overdetermined by hospitals' institutional logics and/or disease progression itself. This does indeed suggest some form of neoliberal hegemony in the sense of a naturalized and often tacit frame for understanding the world

(Comaroff and Comaroff 1991:23).

The Rami case, however, suggests something somewhat different. Autonomous choice, transparently referential language, and cognitive knowledge were part of Center care providers' fully conscious argumentative strategies. As we have seen, for many at the Center, arguing for particular understandings of patient "autonomy" served as an important corrective to both the bad old days of "paternalism" and to the "extreme individualism" of those pushing for full self-determination at death. Deploying these conscious argumentative strategies in a context of conflicting norms and values certainly highlights the growing power of neoliberal discourse in contemporary French medicine. But in many ways these ideological choices revealed the gap between "neoliberal" forms of human subjectivity and care providers' much more ambivalent assumptions about language and personhood. Palliative care in the Center was shot through with fears about the power of words, assumptions about human irrationality, and skepticism about the possibility or even desirability of individual autonomy, particularly in a medical context. As a result, while explicitly criticizing the failure of transparent communication with the Ramis, Center caregivers also constantly conjured up frameworks in which words could potentially kill, and patients required protection and even paternalistic care. Thus Laure could yell in frustration that the key to the Rami case was better communication while simultaneously acknowledging words were not and might never be transparent modes of communication. She could also insist on the centrality of cognitive knowledge and autonomous decision-making while reminding everyone that sedating Monsieur Rami was in his best interests, regardless of how he or his family understood those interests. This seems a far cry from Nikolas Rose's assertion that, at least in the West,

> Despite ... ethical pluralism ... diverse [ethical] regimes operate within a single a priori: the "autonomization" and "responsabilization" of the self, the instilling of a reflexive hermeneutics which will afford selfknowledge and self-mastery, and the operation of all of this under the authority of experts who claim that the self can achieve a better and happier life through the application of scientific knowledge and professional skill. (1998:157)

To the contrary, there seems to be no single hegemonic framework that could explain all of the ways that care providers talked about and cared for Monsieur Rami. In fact, the various ethical normativities at work among the Center's medical staff seemed to rest on plural assumptions about personhood and language.

France and French medicine may be increasingly neoliberal; but at least some French care providers have not fully internalized neoliberal understandings of language and subjectivity. The Rami case even shows that seemingly neoliberal frameworks for understanding what "care" is, what patients are, and what language does can actually be used in the service of ethical normativities that hardly have the cultivation of the individualized, autonomized self at their core. The chaos around Monsieur Rami's death shows how, where, and why doctors and nurses use "choice" and "autonomy" as a critique of the very paradigm that those terms are supposed to scaffold.

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Endnotes:

(1) I have disguised the city and the institution in which I did my research. All names are pseudonyms.

(2) In the context of southern French cancer care, the palliative care team I got to know dealt almost exclusively with patients for whom no "curative" treatments were left. These patients were not always actively dying, but palliative care is still sufficiently stigmatized and scarce in France that it is not (yet) part of treatment regimes for chronic conditions.

(3) French medicine has legally and ethically taken the anti-paternalist turn much more recently than medicine in other parts of the North Atlantic world. It is only since 2002 that patients are guaranteed the right to see their own medical records, and patients still play only a minor role in decision-making about medical care (De Vries, Dingwall, and Orfali 2009).

(4) This is actually a relatively common strategy among anti-euthanasia activists, who may both be wary of elevating "choice" and "autonomy" to an ultimate good and nonetheless contest, in Kantian terms, the "autonomy" of those who request euthanasia (Gandsman and Burnier 2014, Gandsman 2016).

(5) Internists and palliative care physicians at the Cancer Center were still talking about the case of a young man who, several years before I arrived, had died from lung cancer. While suffocating, he continuously refused to be sedated. In the end, the night team could not bear to watch him "suffer," so they administered morphine without his consent. While everyone was uncomfortable with the violation of the patient's will, they were equally in agreement that the young man's situation was unbearable.

(6) Berber, also known as Amazigh, is the language associated with the inhabitants of North Africa prior to the Arab conquest. Berber is from a different language family than Arabic, and the two languages are mutually incomprehensible. The question being debated here is whether the Ramis, who were from a Berber family, had enough Arabic or French to understand what was going on.

(7) Eurydice seems to be alluding to the saying "If the mountain won't come to Muhammad, Muhammad must go to the mountain."

(8) In order to better protect patient confidentiality, I never recorded staff meetings. This exchange has been reconstructed from handwritten field notes taken at the time.

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[Please note: Some non-Latin characters were omitted from this article.]

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