2 Hope, Trust, Medical Action, and Care

The Moral Challenges of Practising Medicine Today

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> Being mortal is about the struggle to cope with the constraints of our biology, with the limits set by genes and cells and flesh and bone. Medical science has given us remarkable power to push against these limits, and the potential value of this power was a central reason I became a doctor. But again and again, I have seen the damage we in medicine do when we fail to acknowledge that such power is finite and always will be.
> *(Gawande 2014: 259)*

> More than ever, contemporary medicine has the potential for relief and torture, and this torture is, of course, always carried out in the name of possible relief.
> *(Our translation, Sicard 2012: 500)*

Isha, a 12-year-old boy, was a patient on the hematology-oncology ward in a leading pediatric hospital in Canada. He fell ill shortly after his ninth birthday and was diagnosed with leukemia. Chemotherapy and radiation proved insufficient, so Isha underwent a bone marrow transplant. Following a relapse, Isha's mother, Aanandhi[1], pleaded with the oncology team for a second bone marrow transplant although the protocol for second transplants did not favor a new graft. Aanandhi was very proactive in searching for alternate medical strategies and hoped that

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[1] Aanandhi, her husband (Isha's stepfather), and Isha immigrated from South America to Canada a few years ago. Aanandhi's family (her mother and brothers) also immigrated, some to Canada, others to the United States. Aanandhi, her husband, and Isha are fluent English speakers.

> Isha would eventually overcome his invasive and life-threatening illness. Her relationship with the healthcare team was somewhat tense; she did not think they were doing their best. As Isha's medical dossier (2007–2009) affirmed, "there are no curative therapies available for this unfortunate child. I (the treating doctor) hope the family will come around to our suggestion of palliative therapy." Yet support care was rejected by the family and experimental treatments resumed. The healthcare team experienced conflicting interests: those of the mother versus those of the young patient. (Field notes, Toronto, November 2009)

Isha's story and many others, as well as several encounters with healthcare providers (HCPs), gave way to the question at the core of this paper: How do HCPs portray their moral role with young and old patients where uncertainty and great illness are part of everyday life? This question is raised in a context of medical and pharmaceutical progress where the boundaries between disease-directed care and palliative care are porous. The chronicity of once lethal illnesses transforms the therapeutic project, where prolonging life is often the consensus and where death is largely concentrated in old age, although not exclusively. Questioning this moral role is also part of a societal context where "dying with dignity"[2] and autonomy are strongly valued. Beyond the promotion of a contemporary ideal, "strong democratic" values support this "dying with dignity" in the intimacy of care, as "a conception of human dignity that makes possible a journey to the edge of death" (Our translation, Hirsch 2012: 16).

When faced with bleak prognoses, doctors may resort to a palliative approach by offering active treatments that prolong life for a (short or long) time while ensuring the most comfort for their patients. They may also choose medical action as research and scientific innovation foster hope, which in turn feeds trust (leading to a bond between the family and the doctor), which feeds hope. This spiral causes HCPs to want to honor this trust and hope by outplaying the prognosis, if at all possible.

Taking care in these uncertain paths is also a challenge. In an attempt to reconfigure the patient-family-doctor relationship into one of partnership where decisions evolve horizontally, poor prognosis, technology, and trust may become allies in distancing all parties from what Gawande (2014) calls "what matters in the end". The HCPs we met with were engaged in supporting families who had to negotiate these uncertain paths and in doing so sometimes abandoned their patients. Hirsch's (2004) call for non-abandonment[3] is not an easy one. And perhaps, room must be

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[2] Commission spéciale sur la question de mourir dans la dignité, Assemblée nationale du Québec (assnat.qc.ca). Rapport *Mourir dans la dignité*, 2012: 11. https://numerique.banq.qc.ca/patrimoine/details/52327/2103522

[3] Hirsch, French professor of medicine and medical ethics, refers to this duty of non-abandonment as a core ethical stance. It is a moral (and political) commitment required by the medical profession, if "we" are to live in an environment (such as the hospital) of solidarity, humanity, solicitude.

made for another perspective in this partnership, one that acknowledges from the onset the legitimacy of supportive care alongside disease-directed care in the area of life-threatening and life-limiting diseases. Yet, families tend to reject palliative care because it is strongly associated with end-of-life care and death. Paradoxically, if it were implicit to all who enter the realm of such illnesses that death is a possibility, life would perhaps find itself enhanced.

The overarching weight of biomedicine, the promises of research, and how this impacts the standard of care give way to a whirling spiral of healthcare drivers (Kaufman 2015)[4]. Both medical staff and families are entwined, bringing them forward into action as the only path even when (near) death is the probable outcome. Again, Gawande (2014) reminds us of our mortal condition: thinking of medicine as a support to life is perhaps a preferable ethos to that of sacrificing time now (with never-ending treatments) for time tomorrow.

The *colloque singulier* (doctor-patient bond) that frames the care provider-patient relationship is a core feature of the medical code of ethics (Hardi 2013). This bond may be challenged by emerging and ordinary therapeutic possibilities. These possibilities may also challenge the meaning of care that refers both to taking care (of someone), in relation to the other, and a therapeutic action aimed at a specific disease or bodily function (Worms 2010). Beyond medical progress, when the ultimate goal of medicine is to maintain life or not to let die, where and when can life coming to an end be acknowledged? These possibilities and in some ways the moral goals of medicine are entwined as strengths and weaknesses of this same medicine. They provide hope while distancing recognition of our common finitude. Can it be otherwise?

Much can be said regarding the moral role of HCPs. If we accept that morality refers to conceptions of right and wrong, just and unjust, acceptable and reprehensible, these conceptions are in turn based on values considered fundamental in a given environment. From these conceptions derive norms that define acceptable practices and, in so doing, we say that morals guide individual and collective practices (Massé 2015). This reminds us of the always situated character of morality (Ricoeur 2001a) or to put it differently, the local anchorage of morality and by extension the plurality of local moral worlds (Kleinman 1999). Now, if the encounter between HCPs and patients is to be a *colloque singulier* as understood by Canguilhem (2011[1966]), a perspective that is far from unanimous (Foucault 1966), this encounter is nonetheless al-

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[4] We are referring to Kaufman's (2015: 6–7) Chain of Health Care Drivers: (1) Biomedical research industry, (2) U.S. federal health insurance program and private medical insurance, (3) Reimbursable therapy by insurance as standard of care, (4) Standard therapies become ethically necessary and difficult to refuse. Although our local medical system (in Quebec) is public, medical insurance companies may offer better hospital facilities and give access to private ones, but they take no part in therapy management.

ways situated with a diversity of HCPs and patients at its heart. Koksvik (et al. 2022) nonetheless refer to the prominent place of action in medicine, an "action ethos" that promotes active treatment over therapeutic abstention. They also mention the sharing of information with the patient and the search for a certain horizontality in the contemporary care provider-patient relationship as an integral part of their moral role as HCPs and "taking care". When serious illness occurs, can death be part of this "taking care"?

Regarding the particular settings explored in this paper, where young and older patients as well as their caregivers are challenged by poor prognosis and end-of-life issues, how do physicians and other HCPs perceive and negotiate the tension between life now and prolonged life? How do they perceive their moral role? What is right? When is it enough? Can a "good life" embrace letting go and allowing a person to die?

In this chapter, we seek to understand the moral role of HCPs in the context of serious illness and poor prognosis. We explore the imminent moral issues of end-of-life decision-making and question whether there is a threshold at which it becomes legitimate to consider death and how this threshold defines what is "acceptable" at the end of life. These questions are supported by various ethnographic studies conducted in pediatric (Fortin) and geriatric (Lessard) settings. They allow us to consider the instability of notions of "good" or "right" in the practice (or in the moral role?) of HCPs when a patient is going through a major illness with a poor prognosis.

Thus, we invite the reader to delve into the realms of children and older adults. With children, we examine the moral role of HCPs and how this role is transcribed into practice. We then explore with the older adults how decisions about therapeutic orientation are constructed around a moral evaluation of what is considered right and enough. Finally, we offer a discussion of what we call "the moral threshold of acceptability".

The setting

The data and thoughts shared in this paper stem from ethnographically informed studies carried out in both pediatric and geriatric settings. Fortin's work in pediatric settings across Canada (Montreal, Toronto, and Vancouver) and in France (Paris) between 2004 and 2020 focused on the many challenges of high-tech medicine, particularly in hematology-oncology and intensive care units but also in general pediatrics and palliative care. Lessard's work focused (and continues to focus) on practices surrounding older adults who were dying in a geriatric hospital ward and a long-term care (LTC) facility in Montreal (2017–2018). She is specifically interested in the moral aspects that promote or hinder end-of-life care for older adults living with multiple chronic and degenerative diseases. In contrast to the pediatric environment, where there seems to be few (or no) limits to therapeutic action, both the geriatric unit and the LTC home favor a medical posture of humility "with regard to power over life" (Collège des médecins du Québec 2008: 22) that embraces the limits of medicine, although everything seems possible in our medicalized world.

For these studies, long-term observations and (many) one-to-one interviews with HCPs and families formed the basic data. In addition, taking part in many informal discussions, various team meetings, ethics consultations, and an array of teaching activities made the hospital environment somewhat a home milieu over time. While Fortin's research topics favored collecting data over time and included diversity issues (Can the clinic be a space of plural values and norms?), both authors focused on the decision-making process when facing poor prognosis, mostly in relapse episodes among the youngest children and older adults.

In both settings, young and older patients as well as families and doctors bond in decision-making processes: in both cases, the therapeutic possibilities seem never-ending, once again illustrating that how and when to stop or when to embrace a palliative approach is a complex issue. How doctors and other HCPs perceive and negotiate this tension between life now and prolonged life may, in turn, challenge the notion of care and its ethical stance.

Realms of the young

Advances in pediatric haemato-oncology allow glimpses of cancer as a controllable chronic illness rather than a lethal disease (Fortin and Le Gall 2022). One treatment follows another without necessarily seeking to "defeat cancer". Are we perhaps at the point where we want to defeat the finitude of life at all costs?

Even if therapies are announced as experimental, the hope they sustain seems to underscore the fact that they are … experimental. Can a mother or father say "no" to these therapies? Is it too much to ask of them? Hope is inspired by medical quests (DelVecchio Good 2001). It is at once needed when facing poor prognosis and detrimental to generating alternate care paths from active treatment to life enhancing treatment. Hope is also nurtured by the trusting relationship, so dear to HCPs and families alike and central to the patient-family-HCP partnership, that guides the decision-making process. This trust nurtures hope: for a life to come, whatever that may be (Mattingly 2010). So, in a way, a strong family-HCP relationship as well as medical progress team up in sustaining hope that may, at some point, inhibit therapeutic options aimed at improving the patient's quality of life rather than a disease-directed approach (Sercu et al. 2018). Yet, as Fortin's fieldwork has revealed, we have both hope and sustained aggressive action, although some of this action is in-tended to improve life (palliative intent through active care).[5] How do HCPs perceive their moral role in such settings where disease-directed action prevails even when (near) death is the probable outcome?

Clinicians' moral worlds

Some believe that the doctor's moral role is to dialogue with the patient, convey information, and explain possible treatment options, all the while putting the patient first.

> In my opinion, the doctor's moral role is to engage in a dialogue with the patient in which they provide […] all the objective data available […] not just objective elements, but elements of professional experience. And then, their moral role, in my opinion, is to ensure that the discussion with the patient includes the patient's values and experience and that in the end, a decision is more or less made and that the modalities are also more or less defined as to how this decision will be challenged if new elements appear or if people are tired with the decisions that have been made. (Dr D., senior physician, Montreal, May 2017)

It is important to listen to one's patients because the therapeutic trajectory can move depending on their understanding of the situation and their changing needs. This attention is not given once and for all, it must be situated and resituated as the clinical context changes.

We are referring to the patient, but our fieldwork indicates that it is usually the parents who want to try everything. Where is the patient's voice in such situations? Should we abandon the patient to support their parents?

Yet, according to Dr D. until recently, with the explosion of treatment options in oncology[6], doctors didn't "decide" anything. If there was a treatment protocol with proven efficacy to treat the disease, the protocol had to be applied. So the clinician's moral duty here consisted of being well versed in the medical-scientific literature. Otherwise, there was the possibility of a clinical trial. Parents, who "share a culture of innovation with us", generally tended to favor this option, he says. Thus, when faced with these two options, "we go ahead with the treatments". When there is no known treatment, a decision must be made, and "the vast majority of parents and patients choose what is possible". In doing so, "we are not abandoning the patient", we are

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[5] Hope as a key issue in the practice of medicine is further discussed in Fortin et al. 2021.

[6] Advances that have given rise to treatments that are generally less toxic, unlike those of the past, which were usually much more toxic and deleterious for patients.

giving them a chance, however slim, to overcome the disease (for a time), especially in a new context where the toxicity of these possibilities is reduced.[7]

The moral role of the clinician is also interpreted by some as the cornerstone of any therapeutic relationship. The physician is a guide who bears a responsibility:

> It's a huge role—you can't make mistakes. Thank God, the weight and responsibility are collective—I'm not alone as a doctor [we are a team[8]], but [the fact remains that] when you're in a relationship with a patient, as soon as you're in a therapeutic relationship, you're a doctor. We're rarely 15 doctors. […] And so, your role is a major one. You absolutely have to be aware of that. That we have a moral role. […] We will influence. And influence in a major way. You have to be aware of that […]. (Dr H., senior physician, Montreal, June 2017)

Similarly, a colleague stated that "this power should not be abused" while also saying that it is his duty "to honor the trust" that parents demonstrate (Dr O., senior physician, Paris, November 2019).

This responsibility extends to "bringing about acceptance", that is, communicating the possibilities:

> In fact, your major role as a doctor in this triangle, this partnership [with the family] is to get the patient (which is often easier) and the parents to accept the situation. […] From the very beginning, you open up the possibilities […], you inform them about everything. You want the child to get out of the situation—that's not the problem—but you inform them of the possibilities. One of the possibilities is healing. It's a possibility, okay? There is also the possibility of not being cured, the possibility of chronic illness, the possibility of death. And the more things progress, the more they evolve, the more things move towards these different possibilities. But it is absolutely necessary to make them visible, to make them meaningful. People must make these possibilities their own and they must not fight against them. (Dr H., senior physician, Montreal, June 2017)

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[7] And we remain in a curative perspective, or at the very least, in an impression of a curative trajectory.

[8] (Medical) team decision-making is not discussed in this chapter. Again, in Fortin et al. 2021, we discuss this issue and affirm that voices that call for action in team meetings seem to carry more weight than others. Actually, silences in meetings generally foreshadow some kind of disagreement but it is rarely voiced as such. This is particularly so in field work that took place in Québec. In the French context, although meetings remain top down (like in Quebec), disagreements amongst physicians are generally voiced (in a lively manner) but it is unclear how treatments are furthered after these discussions take place. Our data is limited in this regard (field work having been interrupted by COVID pandemic). In light of what was collected, we could state that although alternate treatment perspectives may be voiced in team meetings, the vivid hierarchy within medicine leaves the decision to the "top" physicians.

Paradoxically, this same physician said, “if there is a one percent chance of beating the disease, we should go for it”. In doing so, the recognition of death goes hand in hand with therapeutic activities that are oriented towards healing, even when this is not an illusion but a very distant possibility. Note that the cases reported here are generally not situations of first diagnosis of a disease, but rather situations of relapse (first, second, third … after a period of remission of highly variable duration).

(Biomedical) research and clinical trials are no strangers to these postures. Subscribing to them gives rise to choices about how the patient and their family want to experience what happens next. These choices create a duty for the doctor:

> Often, of course, families are not sure how to judge the value of a certain research protocol from a scientific point of view. So, they ask me, “What would you do if it were your child?” That’s the basic question, always … and I have to answer, “It can vary depending on the disease [the doctor then hits the table], depending on research projects as well [idem].” […] My goal is to get all three messages across palliative care, standard care, and research. And then, depending on what the family wants, I will expand on one of these aspects. […] It’s a dynamic thing, that is to say, it can vary depending on the person in the family with whom I’m talking. Also, the mum and dad, they don’t necessarily have the same point of view. The child, when they’re small, they’re often taken out of the discussion by the parents, as they prefer to keep things between them and the doctors. But when children are older [over 14 years old in Quebec], like Arthur[9], they are able to make their own decisions, and we really take into account what they are asking for and what the parents want. (Dr T., senior physician, Montreal, April 2017)

A few blind spots

For some, information sharing and support are the driving forces. For others, the driving force is based on the “best interests of the child” even if that means, paradoxically, going a bit against the parents’ opinion (Dr D.). This best interest does not mean neglecting the duty of an alliance with the family, an alliance that is “built and rebuilt” throughout the therapeutic trajectory. To quote a nurse in a hematology-oncology care unit in Paris:

> The challenge of advanced medicine is not [only] to see the research but to see the best interest of the child first and foremost […] and to always keep that in mind. What is in the best interest of the child? Is it that their parents be there during care or is it in the best interest of the child to tell the mother, “Well, if you

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[9] For an in-depth account of Arthur’s story, see Fortin and Le Gall 2022.

> don't mind, please leave because things go better when you're not here". (Our translation, Angela, nurse, Paris, December 2019)

At the same time, a doctor will say without question that the pediatrician must look after the child, ensure their care, and that the parents are partners here. But if the parents are opposed to a therapeutic directive which will have an impact on the quality of care and the child's future, "the parents must be disregarded" (Dr B., senior physician, Toronto, October 2009). A colleague agrees, "I have a responsibility in society to defend the child." (Dr G., senior physician, Toronto, September 2009). However, this emphasis on the child's "protection" is not given outright, as Isha's story suggests:

> Joan [nurse] informed me that the parents, especially the mother, were always pushing for treatment. They applied for a drug in the U.S. The [medical] team had been reluctant to give active treatment for a while now and actually considered Isha [a 12-year-old boy] a palliative patient. Regarding this specific drug from the U.S., the team was against giving it because they knew it could have a severe impact on the boy (and thereby reduce his quality of life). His mum, however, insisted upon it. The nurse actually said that "she [the mother] had to do it," meaning that it was her role to fight for her child.
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> Interestingly, Joan mentioned a few times that the boy expressed "tiredness" and "wanting to go home" to the medical team. He, however, did not express this when his mother was around, and she either did not know, or did not take it into consideration.
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> Ultimately, Isha was given the new drug and, sadly, went into multiple organ failure, which was one of the known risks of the treatment. Joan said that he died quite quickly. (Observation notes, oncology unit, Toronto, November 2009)

In an interview, Joan stated:

> I struggle with the fact that [quantity of time prevails over quality of time]. Sometimes we are really pushing that research and pushing these medical innovations but not necessarily able to explain to families what this might look like. And that yes, there's this that might be able to give you more time, but what kind of time? I feel like that's one of our weaknesses, it's really explaining what kind of quality that child is going to have.

And regarding Isha:

> We had a patient where we all struggled with the way we had moved forward with the treatment. We knew there was no chance to cure, and we felt that the

> primary doctor was offering too many options for the family and that Isha wasn't receiving any quality of life. And the nurses struggled with that because he often voiced to us that he didn't want any more, but of course, when the physician would ask, Mum would be there, and he wanted to please Mum and he knew she wanted everything. So, we had an internal struggle. […] I would try to share some of the comments that her child had made with her, trying to do it with as little judgement as possible, because it was very difficult, but she was … it was … [a difficult relationship], it wasn't the best example of a really good therapeutic relationship … so it made it really, really challenging to have those open discussions with her. She really could not see our nursing perspective. (Joan, senior nurse, Toronto, October 2009)

When asked about the ethical challenges of contemporary hematology-oncology practice (it was 2009 at the time), a young doctor in the same unit spoke of Isha:

> I mean it's oncology, so there's ethics every day and every minute. Probably the big issues I've come across just over the last year or two are usually around either patient or family autonomy or around end-of-life care. So, you know, from an autonomy point of view, a family who doesn't want their child to know that they have cancer or who doesn't want the child to know that they're dying or etc., etc., etc., and all the sort of issues that arise from an end-of-life care point of view, when there is a disconnect between … in a situation when a cure is no longer a feasible option for a particular child. What then is in the child's best interest when the treating team has a different idea of what that may be for the child or the family? So you know, when a cure is not an option, is giving toxic medication to give [sustain] hope appropriate? And if a family desperately wants this experimental very toxic chemotherapy to be given, even though you really don't think there is any realistic cure and you think it will just bring side effects, what do you do? (Dr G., junior physician, Toronto, October 2009)

Realms of the older adults: Are they so different?

In the geriatric context, the incurability of disorders affecting older people who are admitted to geriatric units or LTC homes is common. While we can hope for a relative recovery, especially for people suffering from acute illnesses, or to slow down the decline of chronic illnesses, people living in these settings will not be cured of their conditions. It is around quality of life that efforts will primarily be concentrated.

Although most patients were frail older adults, palliative and end-of-life care was usually only initiated hours or days before death, when offered. According to one long-term care doctor, this "end of life" is usually more of a decision than an unequivocal state of affairs. Like him, many HCPs question what the end of life is, or at least observe the absence of clear markers that delineate it. This doctor then evoked two types of life endings: the unavoidable and the avoidable. The first results in an inevitable death, despite the care provided. The second is a death that could have been avoided if the therapeutic intensity had been different. In this second case, it is a matter of choosing not to carry out certain interventions that could have prolonged life. We may therefore consider the acute care episode as a window of opportunity as Kitzinger and Kitzinger (2013) would say, where the withdrawal or abstention from treatment leaves room for the possibility of dying.

In short, according to doctors, recognition of the end of life is a matter of clearly having no more possible therapeutic options or, alternatively, not wanting to consider possible options for prolonging life. It is the critical point where one is faced with two options and must choose between prolonging life or considering death.

Circumscribing the end of life implies distinguishing the sick from the dying, the curable from the incurable (Rossi 2010). These boundaries are shifting and porous. The passage from one category to another gives rise to a change in the person's status (and level of care) and, in so doing, affects the ways of doing and saying of the actors involved. Beyond an operational definition of the sick and the dying person, the challenge is to recognize the transition from one category to the other at the "right" moment. Thus, according to the perspective of HCPs, relatives, and sometimes, older adults, there is a critical point of what is considered right and enough where the recognition of dying becomes a moral issue. How can we recognize that life is ending beyond the clinical notion of end of life?

Ms Moretti's story

Ms Moretti, a 90-year-old woman and with an advanced major neurocognitive disorder, refused to eat and drink. These refusals had been occurring quite frequently for a year and were usually accompanied by an infection. Her family, who was very present, demanded active care (antibiotics and artificial hydration) during each acute care episode. At a certain point, the family was considering the use of a gastric tube to allow Ms Moretti to be fed. These situations raised questions among many HCPs about the appropriateness of the interventions, especially with respect to Ms Moretti's quality of life. As a nurse stated:

> She (Ms Moretti) was a resident […] I could see that she was not able to express herself, but her family, I thought that they were very hard on her. She was given invasive treatments. You could see in her eyes, in her look, that she was tired. I found that terrible. But we can't judge, they are human after all. The doctor managed to convince the family to let her go a little bit. But it was really difficult. It was spread out over several months; there were IVs, a lot of treatments. I found it invasive to keep her alive. She had no quality of life. She stayed in bed, we got her

> up, she was entirely dependent. (Our translation, Mel, senior nurse, LTC home in Montreal, August 2017)

According to several HCPs, Ms Moretti was kept alive for a long time because her family wanted her to receive active treatment. The head of the unit and the doctor believed that it was essential to "put their foot down if her health condition deteriorated again" and speak out in favor of comfort care over active care. They had to support the family on their journey towards accepting Ms Moretti's impending death.

One doctor felt that it can be difficult to decide what to do when you don't know the wishes of the sick person.

> So, at that point, I think that we can't go completely against what the whole family wants when the person can no longer respond, especially if we don't know what that person would have wanted in that situation. […] For example, if a family asks us to place an IV on a patient who is at the end of their life, is it inevitable that they will die? Well, obviously, if we put in an IV, we delay that deadline because we are hydrating artificially. (Dr Damato, LTC home in Montreal, September 2017)

A few days after Ms Moretti's nth refusal to eat and drink, the doctor met with the family and explained that Ms Moretti's decline was part of the normal course of the disease and that no active treatment would benefit her. End-of-life care was offered. Ms Moretti benefitted from this care for a few days before taking her last breath surrounded by her loved ones.

Although many doctors and nurses have testified to the family's central role in decision-making, the final decision remains a medical prerogative, at least for seniors. The concept of shared decision-making and partnership is ambiguous. The information shared with the family by HCPs is weighted according to what the team believes the family is able to accept.

The healthcare team's decision[10] to stop or refrain from treatment can thus give the impression that it is part of the natural course of a terminal illness. One doctor's words speak for themselves:

> It takes the guilt out of it if you tell them that this is what you think, this is where you are, this is what you should do. It's often a relief for them not to have to make that decision themselves. It's not that we decide 100 percent. Those who object will object. […] But for others, it takes the weight off their shoulders when we decide for them. (Dr Damato, LTC home in Montreal, September 2017)

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[10] Decisions among members of the health care team regarding end-of-life care are generally made by consensus. However, some differences may emerge when physicians follow the wishes of families (to continue care) while nurses may not believe this is in the best interest of the patient.

In this type of situation, debate is avoided, and the decision does not have to be justified. The family defers to the recommendations of the HCPs as to the steps to be taken, and thus does not have to take part in the final decision, that is, the decision that would mean the end of their loved one's life. This mode of action, while it may be described as "paternalistic", relieves the family of the tragedy of the undecidable.

HCPs see their moral role as one of protecting the ill person who can no longer express themselves, or even of advocating for the respect of their wishes, when known or still perceived (then described as a fatigue of living). They also see it as "doing good", with respect and without judgement.

What does it mean, especially when the approaching death is not recognized by all? How does the moral role of HCPs translate into practice? What legitimizes, from a moral perspective, the option of considering death? What is the threshold that defines what is "acceptable" at the end of life?

The moral threshold of acceptability

Isha's and Ms Moretti's stories illustrate the discomfort that some HCPs experience when active treatment continues while death looms. Isha's HCPs, however, did not challenge Isha's mother's request for the drug, nor did they warn her about the fatal consequences it could, and did, have on her son. On the other hand, in Ms Moretti's case, after several episodes of active care, the caregivers decided, by mutual agreement, to bypass the therapeutic possibilities by proposing that there was nothing more to be done. Ms Moretti was then able to live her last moments with her family while benefitting from comfort care. Does this mean that, unlike children whose lives are considered precious, the lives of older people are expendable? Isn't this sacredness, or lack of sacredness, of life, so typical of the global North and its perspective inherited from Enlightenment ideas prevalent and formed in the 18th century in the West? It is rooted in the positive connotations attributed to childhood as opposed to the negative connotations attributed to old age, which is associated with dependence, senescence, and frailty (Baker and McCullough 2009)?

According to Biehl (2013), there are categories of people who are allowed to die because of their perceived lower social status. Glaser and Strauss (1964) referred to the different social value of the dying regarding ethnic affiliation in particular, but also according to age group. More recently, Králová (2021) reiterated the inequalities in status and the impact of these inequalities on the experience of care, despite the dynamism and agency of the people concerned. Kaufman (2006: 23) also proposed that neurocognitive disorders (dementia) act "as a rationale for facilitating death."

If there is (cultural) ambivalence about whether (an older adult's) life no longer having meaning is reason enough to consider death, it is sometimes the very status of "living" that becomes difficult to pin down, define, or even justify (Soulières 2019).

And from the perspective of Lessard's field, this is not only relevant in the context of people who suffer from neurocognitive disorders, but also in the context of older people whose physical decline is very advanced.

It is this moral threshold, where it becomes more acceptable, legitimate, even desirable, for a person to die, that we wish to focus on. In our work, some people are looking for a threshold at which it would be right to stop curative treatments. Others question the very idea of having to stop, as the possibilities are now minimally toxic, or minimally invasive, reducing the notion of therapeutic overkill to nothing, or almost nothing. It is also around this threshold that "regimes of living" (Lakoff and Collier 2009), or perhaps here we could say "regimes of dying", seems to be operating to give substance to an action guide of negotiation of what is considered right and enough. Moreover, according to Broom et al. (2014), negotiation becomes more important when the lines of action are uncertain, which is particularly the case when it comes to pursuing futile treatments and redirecting care. Care, especially that which is played out at the very end of a senior's life (particularly in the case of Ms Moretti), often seems to be family-oriented to some degree. The subjectivity of the (sick) elder is relayed to the representations that the HCPs or relatives have of what is acceptable for the older person.

If this threshold is difficult to define for older adults, how can we consider this same threshold for children? How can we explain the silence of the HCPs around Isha? When does it become acceptable to tend towards a comfort perspective rather than a curative approach? Is their silence intertwined with the tension between a horizontal vision of the HCP-patient relationship rather than a vertical, top-down approach? Does this partnership with the family become deleterious to the patient at a certain point? Is it similar to the hope of a miracle treatment, however improbable? Although Du Pont-Thibodeau (2017) has demonstrated that end-of-life care is more easily proposed and implemented for babies in neonatology than for older children, Fortin's results show that action is often required for children of all ages, at least in oncology. Don't some pediatric oncologists say, "if there is a one percent chance of beating the disease, we should go for it"? Among the older adults in our study, the end-of-life stories where negotiation took place were those where the integrity of the body seemed particularly compromised and where consensus on the course of action to be taken was not a given at the outset. In all the stories documented by Lessard (2021), the legitimacy of dying was built around the threshold at which action was no longer justified, when the integrity of the body was compromised, and quality of life was absent (from the point of view of the physicians and sometimes also of the relatives).

According to Rose (2001), human existence, whether individual or collective, is based on bodily existence. This would explain why the immobile, suffering body, in great decline becomes from then on the place where the moral threshold of what is considered right and enough is manifested, at least among older adults. Among children, another dynamic seems to be at work, one in which youth and its importance in our societies prevails over everything, as in Isha's case. In this way, if the inert, lifeless body of an older person seems to flout human dignity and therefore makes death morally acceptable, it seems that this morality is less well defined among children. And even among older adults, acceptance of an impending death is often delayed and delays the care that could alleviate the suffering, if not of the family members, at least of the patient.

Suffering of the dying older person cannot be legitimized and accepted as it is no longer an obligatory passage towards a better life. Unlike with children, for whom any hope of recovery, however slight, can lead to a denial, by both physicians and parents, that the child's suffering will be endless. Hence their rejection of a perspective of care aiming at comfort and life now rather than the hope of a life after. Suffering becomes from then on either "tolerable" or "intolerable" and, thereby, a denied or legitimately accepted death (Bueno-Gómez 2017). This makes it an object that is subject to moral judgement.

The attainment of the moral threshold of what is considered right and enough is subjective; it depends on who makes the evaluation and that person's judgement. Not all HCPs have the same perspective on this moment. It is a work of interpretation that takes place over time, based on evaluation criteria that are objective and biomedical as well as subjective, such as quality of life and the patient's perceived or expressed desire to die. This evaluation is also experiential, i.e., it is part of the biographical history of the people making the judgement. This moral evaluation is also inscribed in power relationships between the different actors, care services, and types of curative or palliative medicine.

In the end, we come back to a tension that has been discussed many times in our fields of knowledge, that is, the attention paid to life in itself or to living (Fassin 2000). Despite the sustained work of HCPs with both children and older adults, this tension between life and living remains despite the progress of various policies affirming the fundamental right of people of all ages and all backgrounds to "die with dignity". The fact remains that the moral role of the various protagonists is inscribed in a plurality of worlds: at its center, there is an inalienable reminder of the unique, asymmetrical character of the clinical encounter, between the person who is suffering and the one whose knowledge and know-how are aimed at alleviating the suffering (Ricoeur 2001b). Perhaps we could simply write that "taking care" is a common value in life and death and that this taking care takes precedence in the moral field of HCPs. This care is a key notion both before and after life and dying; it is at the heart of the tension between life now and prolonged life.

Concluding remarks

This incursion into the realms of pediatrics and geriatrics where terminal illness, life, and death are juxtaposed, reminds us of the extent to which therapeutic orientations are mixed with possibilities. In a therapeutic context that values a multiplicity of voices, we have questioned the moral role of the caregivers and, even more so, the moral roles of HCPs.

Regarding the pediatric settings, it seems that the French team, while listening to the families, remains "top down" in its intervention, taking "the best interests of the patient" to heart. The Quebec and Toronto teams, on the other hand, are more oriented towards a horizontal relationship with the family, in keeping with the "patient as partner" approach that the Quebec healthcare system holds dear. Of course, the patient is at the heart of everyone's concern, but unlike the French team, the families' choices seem to take precedence over those of the pediatric patients. Nevertheless, as Clemente (2015) observed, when faced with a poor prognosis, optimism prevails, and death is overlooked.

In both Montreal and Paris, the therapeutic orientation is still compartmentalized within the curative; there is a lack of input from those who could advocate for patients or alternative therapeutic strategies, particularly a palliative orientation. Yet, the duty of non-abandonment is an inclusive duty, attentive to a plurality of voices, capable of opening up a discussion on possibilities—not only in the field of curative care but also in that of support (Jouannet 1999). It is taking care (in all its complexities) that is at stake, care as a moral commitment, as a duty of non-abandonment.

As for the realms of the older adults, as in Ms Moretti's story, the doctors' decision to limit the curative approach spared the family the impression of giving in to death rather than doing everything possible to maintain life. If the "top down" decision-making mode used by the attending doctor can be described as paternalistic, it nonetheless provided support for the family and a way to better cope with the impending death of their loved one. "Doing good" does not necessarily mean providing active care or comfort care, but rather following an approach that must be constantly validated depending on the history of the patient and their loved ones.

However, the fact remains that both Isha's and Ms Moretti's stories give us glimpses of the encounter between young and old age in that the prolongation of life seems to be a central value that guides action when doubt hovers. This doubt may or may not be shared by all HCPs, by HCPs and the family, or by HCPs, the patient, and the family. How then can we move forward if not by recognizing a potentially dominant posture, that of taking care as a primary value? Can we think of the encounter between patient and caregiver in this light?

The discomfort of death is certain—clinicians approach it with difficulty, as do families. Could we consider death (even faintly) as a possibility alongside serious illness? And would a collaborative approach guided by horizontal relationships among HCPs be a way to do this?

In short, beyond these issues or perhaps through them, our "multi-faced relationships" to the numerous complexities of medicine further (or contribute to) our understanding of a world constantly in the making. As Kehr et al. (2018: 2) and many others have asked: "How do moral, medical, political, and economic values and norms shape health-related subjectivities and processes of subjectivation, and how do understandings and definitions of being human change accordingly?" In this way, the many challenges of medical decision-making are a window into how medical progress shapes our views on life, death, and dying. They also provide insight on medicine as a political site as well as a moral one.

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