

CHAPTER 2. BETWEEN REASON, SCIENCE AND CULTURE: BIOMEDICAL DECISION-MAKING

Sylvie Fortin

ESKA | « *Journal International de Bioéthique* »

2015/4 Vol. 26 | pages 39 à 56

ISSN 1287-7352

ISBN 9782747225496

Article disponible en ligne à l'adresse :

<http://www.cairn.info/revue-journal-international-de-bioethique-2015-4-page-39.htm>

!Pour citer cet article :

Sylvie Fortin, « Chapter 2. Between reason, science and culture: Biomedical decision-making », *Journal International de Bioéthique* 2015/4 (Vol. 26), p. 39-56.

Distribution électronique Cairn.info pour ESKA.

© ESKA. Tous droits réservés pour tous pays.

La reproduction ou représentation de cet article, notamment par photocopie, n'est autorisée que dans les limites des conditions générales d'utilisation du site ou, le cas échéant, des conditions générales de la licence souscrite par votre établissement. Toute autre reproduction ou représentation, en tout ou partie, sous quelque forme et de quelque manière que ce soit, est interdite sauf accord préalable et écrit de l'éditeur, en dehors des cas prévus par la législation en vigueur en France. Il est précisé que son stockage dans une base de données est également interdit.

Chapitre 2

BETWEEN REASON, SCIENCE AND CULTURE: BIOMEDICAL DECISION-MAKING¹

*Sylvie FORTIN**

INTRODUCTION

In pediatric care, a child's or patient's mother and father are the key interlocutors in the care decision-making process along with physicians, especially when the care will impact a child's longevity and quality of life. When there is discordance between the healthcare professional and the family, the doctor invokes his responsibility towards his patient in order to legitimize the privileged biomedical orientation. Clinicians can also propose different therapeutic avenues to parents, leaving them the choice to opt for one or another path. The proposed options remain within the medical spectrum, often presented as neutral and anchored within formal scientific knowledge.

A significant body of literature has emerged on medical knowledge as a normative value, medicine having progressively imposed itself as an exclusive source of knowledge on health and related social issues (Bouchayer et al., 2004). From science that, through medicine, has come to "dictate the standards of life for its subjects [...] by a knowledge thought in itself" (LeBlanc, 2002, p.75) to the

* Professor, Department of Anthropology, Department of Pediatrics, University of Montreal. Email: Sylvie.fortin@umontreal.ca

¹ A prior version of this text appears in *Migrations Santé*, no. 146-147, 2013 :17-51.

complex relationship between the normal, the pathological, scientific and social norms (Canguilhem 2011[1996]), medical knowledge has become a point of reference, extending well beyond the boundaries of the clinic. This paper reflects upon how the morals or values of healthcare professionals become normative in clinical spaces, amalgamating with medical knowledge to guide the decision-making process in cosmopolitan hospital settings. We remain critical of clinical ethics portrayed as neutral, objective and detached from its context (De Vries & al., 2007). This line of thoughts also rests on the double relation between expert and lay knowledge and majority-minority rapports, the majority as the referent able to define collective norms (Bourgeault, 2004). One can question the place of knowledge within clinical encounters, those of the experts and lay persons, and how these assemblages of knowledge intervene within the decision-making process.

Similar to Edel & Edel (2000), we do not envisage moral diversity as a necessary source of conflict. Through our work here, we survey the plural normative modalities privileged by a contextualized anthropological approach to ethics, such as they are deployed in the “ordinary” (Lambek 2010), “ethics in action” (Paillet 2007). It is in this perspective that we question decision-making within Canadian cosmopolitan hospital settings. How do the hospital norms and values echo the local social, cultural and religious diversity? We will shed light on this question via an examination of critical decisions that arise in the provision of mother-child hospital care. We will see that in the same image of pluri-ethnic urban cities, care settings are also punctuated with a multiplicity of values that accompany the patients and their families from all backgrounds, as well as healthcare professionals. Wishing to grasp these reoccurring logics will help us to better understand the delicate relationship between the individual and the collective, between personal values and established norms, between the majority and minorities. The testimonies of physicians working within intensive care units and hematology-oncology offer insightful views as to how ethical stances, values, expectations and emergent norms are played out in the space of the clinic, influencing the decision-making process in a complex care context where cultures and organizational structures intersect. In order to do so, we will firstly address how healthcare professionals relate to alterity and how otherness bares on ethnical stances, giving way to the decision-making process in clinical settings as a moment of negotiation or non-negotiation of different values and perspectives. A portrait of the care contexts will allow us to better appreciate the different philosophies of care and models of medical decision-making. We will see how different clinical spaces and practice nurture different relationships to time that in turn shape the decision-making process. We will also discuss the therapeutic continuities and discontinuities, favoring the sharing/non-sharing of knowledge. Finally, we question the medical decision-making process affirmed as a scientific rational in opposition to a process guided by affect, culture and religion.

A FEW WORDS ON THE STUDY

Our perspective stems from a multi-sited anthropological study, represented by 175 in-depth interviews conducted with 94 physicians, 55 nurses, and 26 other healthcare professionals, more than two years of observations in care units and over sixty case-studies conducted with families visiting these units during the time of the study.² As a multi-sited study, we incorporated three successive Canadian pediatric hospitals. For each location, we gathered data from intensive care units (ICU) and hematology-oncology wards. In terms of population diversity, let us recall that 31% of Montreal's population is born abroad. As for Vancouver and Toronto where our study also took place, respectively 46% and 50% of the population is born outside of Canada. All three urban centers have pediatric hospitals offering specialized and cutting edge technological care.

The semi-structured interviews with clinicians lasted 90 minutes on average and covered an array of themes, from contemporary clinical practice to the daily challenges encountered, namely in regards to urban pluralism. As for the physicians (the principal reference material for this paper) they were as many men as women (in nearly equal proportions), and two-thirds were born in Canada. The remaining third was born in one part of another of the Commonwealth (or from French speaking European nations for the migrant physicians practicing in Montreal). 85% of this migrant group could be assimilated to the majority Caucasian population. We noted a greater diversity amongst the remaining 15% in Vancouver in comparison to Montreal which tended to be more homogeneously "White". The common spoken language was English for the majority, Montreal being the only French speaking city in the study.

The observations, including informal interviews, were conducted in an in-depth and continuous manner over a period of 4 to 6 months on each unit per hospital location. The daily settings of each unit were documented--its rhythms, uncertainties, intra and inter professional relational dynamics, as well with children and their parents; medical rounds, life at the patient's bedside; various team meetings, notably in regards to therapeutic orientations and family meetings (when relevant to our study). We also shadowed specific professionals one-to-one, during

² Initiated in 2004, the study: *Pratiques cliniques en contexte pluraliste* was funded by the Canadian Institute of Health Research (CIHR: 2005-2011) and conducted with a close collaboration with anthropological, physicians, nurses and ethicist colleagues (Fortin, Bibeau, Alvarez, Laudy, Carnevale, Duval, Gagnon at Université de Montreal, McGill and the Centre Hospitalier Universitaire Sainte-Justine, as well as many other healthcare professionals practicing within different localities required for this study (Montreal, Toronto, Vancouver). A number of assistants have taken a strong hand in the project notably S. Maynard, M.E. Carle, M.J Blain, M. Rietmann, V. Duclos. Many thanks to all for the quality and consistency in their implication in the study.

the performance of their daily routines. This ethnographic data complemented interview material and case-studies. The later incorporate observations, informal and semi-structured interviews with families (parental couples, mother or either spouse) conducted according to their preferences either at the home or hospital. From our observation data, we were able to target families with an overall positive therapeutic relationship with the healthcare team and on the contrary those families with a more polarized relationship. Families were also stratified by those with very young children/patients, school age children and adolescents. We collected children's histories, their illness, and encounters with health services, their hopes and "deceptions."³ Half of participating families were of Canadian, Commonwealth and European origins. The others originated from the near or Middle-east, Asian, the Indian sub-continent, the Caribbean, and First Nations. One third of families could be assimilated to a visible minority group as well as a linguistic minority.

The data was analyzed both intra corpus (each interview analyzed on its own, by professional category, by unit, and location) and inter corpus (triangulating the interviews, observations, and case studies) according to a frame of analysis incorporating initial research themes, but also in light of events and dimensions revealed by the study itself.⁴

DECISION-MAKING

Decisions result of deliberate choices as well as "routine" actions (Kaufman, 2001). They may follow a moment of negotiation with the patient, his family, peers (clinicians) or institutional actors. These decisions can be spontaneous, open and the result of a long process or on the contrary, not openly shared.

It's very very easy to do everything. It's much easier to do it all than to establish limits. It is necessary to know when to establish them. [...] the decision course of the medical team is not at all at the same speed as that of the family's or even the path of certain consultants.

Physician, ICU

Everything such as values and norms must be contextualized. In a similar fashion, decision-making and the doctor-patient relationship are tributaries to structural and organization conditions, professional cultures, and the particularities that

³ We discussed with children only in rare circumstances, their health status were often critical or because they were of a very young age.

⁴ The study also received approval from the ethics committees at all participating institutions.

develop in the nature in the provision of care. Decision-making is also subject to power relations carried forth between the doctor-patient relationship (Fassin 1996; Ricoeur, 2001) and, in an inclusive manner, to the subjectivities present. The locality is equally an important actor in this process, notably when stopping treatments is at issue. The collective silence around the death for example is evoked by certain clinicians as being responsible for the pursuit of futile treatments at the demand of the parents (and we can add sometimes as well certain physicians).

The idea that you can do inappropriate care is always a dilemma, it can tear you apart, it is very stressful. You prolong a life when you know there will be no pleasure for this child, you put in drains and tubes that will allow him to breathe or to be fed and you know that it's just to prolong life. It is an underlying attitude of society that views death as something bad. Death is not natural, death is not normal. [...] It's society that makes these decisions. It says ok, it is necessary to do everything to maintain the child alive or further yet, a society may say NO, its futile. Everything depends on society. Ultimately, these decisions are out of my control as a physician”.

Physician, ICU

Public expectations towards medicine, the medical successes of large pediatric hospitals and the pace of technological advancement often drive parents to pursue treatments, in the hopes of a miracle. That is to say that at the heart of the clinic encounter there are numerous actors, healthcare professionals, the patient, the family and the community, each with his own accompanying values and norms exposed during those decisions which determine care.

Just as the local community participates in the shaping of values that surround the withdrawal of care, the different contexts of clinical practice, the vocation of each unit and their organization also have an impact on decision-making. For example doctors in the intensive care unit are often more inclined to suggest the withdrawal of life support systems or invasive treatments whereas, oncology clinicians advocate for its continuation.⁵ How is it possible to understand these competing perspectives at the heart of the institution itself, often attributed to the same patient (who cross units through the course of their illness)? Do these orientations stem from the same decision-making process?

⁵ We are generalizing for the end of the discussion, but many exceptions nuance these findings.

CARE CONTEXTS

Differing dynamics surround decision-making, from the consultation or non-consultation of the family to the modalities of this consulting in terms of the time and frequency. These dynamics frame the institutional horizons upon which decisions are made, facilitating or impeding the integration of the family in the process. Even though all three pediatric hospitals taking part in our study subscribe to a philosophy of family-centered care – where the parents are viewed as partners in care – it is clear that despite this philosophy, the goals pursued by different units (here intensive care and hematology-oncology units) will set their own precedence upon this notion.

At the intensive care unit (ICU), there are two types of patients: the first are passing through (a few days only) in an acute state, following a traumatic episode; the second group are also in a critical state, but have a much longer stay, requiring significant technological intervention for a long duration following a traumatic episode or related to their illness trajectory. The physicians in this unit work as a team. In some instances though, a primary doctor is designated by the team namely when a patient presents a challenging complex situation (often medical), or requires a prolonged stay. In the absence of this primary doctor, many parents seek information hoping to better understand their child's condition. This team structure reflects the unit's initial vocation of intense care, where the provision of acute care was almost exclusive and where the question of continuity of care, was irrelevant. This structure is also subordinate to an institutional logic: where physicians share their time between clinical practice and research activities as well as staff rotations (total of on-call hours distributed among the available physicians). The nursing staff are more stable and in the ICU, each nurse is responsible for one child all through her work day (evening or night) and possibly for a few consecutive days. Their participation in decision-making remains marginal all the same as the therapeutic decision is a medical prerogative.⁶

This team dynamic imposes a decision-making process defined by the family-staff relationship, much more than the traditional doctor-family-patient relationship:

I believe that the relationship is different [at the intensive care unit] from a traditional doctor-patient relationship. Certain families are really prisoners of this vision of the doctor-patient relationship. But the modern intensive care unit, that's not it. It cannot work as such. Families must have faith in the system. And that system entails the rotation of physicians and nurses, the rotations of technicians, and other

⁶ This being said, some units particularly favor nurse participation in the decision making process and have organizational « facilitators » to make her taking part in the « decision meetings » possible.

healthcare professionals. And that's the relationship. It is difficult because, it is not what people are hoping for or imagine. This is not what is shown on television.

Physician, ICU

Furthermore, due to the nature of the ICU (the status of many of the patients are unstable and in constant evolution), parents are not always included into decisions relating to the care of their child. As underlined by this intensive care physician: *It is only in the serious situations that parents are made to participate in the decision-making, but for the rest of the time it is presumed they will agree.* Another colleague further states that in general, parents are not part of the decision-making process and that most of the time the parent and healthcare professional relationships are one directional:

Often, discussions with families, unfortunately, are conducted with a singular objective, where it is us who say: "OK then, what have you understood? I will give you an update. This is where we are, and here is our plan. Do you have any questions?" Understand, they have a lot on their mind, [and they will respond] : "No, no, it is good, thank you."... Rarely has a discussion happened in the other direction, where we sit down with them saying: "Ok, how are you experiencing this, how are you feeling?" I would say this is a question of time and probably of interest as well.

Physician, ICU

In hematology-oncology, patients have specific illnesses and are generally matched with a physician in regards to his/her area of expertise. As a result, more often than not, each patient has a treating physician who will guide his treatment path even if he/she may be subsumed to a team (submitted, as all, to staff rotations). In contrast to the parents in the ICUs, those in oncology refer to "their" physician with whom they develop a relationship over the course of time. Children are hospitalized at pivotal moments during their illness and visit external clinics but remain with the same treating physician until adult age. Parents also become "part of the team". On site at the hospital, they monitor, document, report any and all changes in the condition of the child. At home, parents pursue treatments, give medication, continuously sharing updates on their child's state with the hospital health care team.

PHILOSOPHIES OF CARE AND MEDICAL DECISION-MAKING MODELS

In the following, we discuss decisions that rest on physicians, children (patients) and their families (mothers, fathers and other significant members). These are “critical” decisions as they stem from paths of suffering and put into question the pursuit or withdrawal of treatment, leading eventually to the end of life. For Payot (2007), this decision-making is shaped by the physician’s views of the ideal patient-family-physician relationship. In this perspective, what is perceived positively or negatively, good or bad, from a professional ethics point of view depends upon what is considered to be the “moral” role for and by the physician in regards the needs of his patient (Pellegrino, 1987).

In the scope of our study, we have documented the philosophies of care which incorporate simultaneously the doctor-patient relationship such as described by Payot (2007), and different decision-making models: paternalism, (which leaves little to no place to the patient during decision-making), informed choice (where the physician communicates the relevant information and the patient independently makes the decision), and sharing model (an inclusive approach of the family). Actualized within care orientations, these different decision-making models may or may not foster the clinical encounter and the negotiation of diverse values that guide such decisions. They also may or may not permit the recognition that plural norms coexist within the clinic during decision-making.

Thereby, less than half (42%) of the physicians interviewed privileged an approach guided by dialogue with the family, occurring two times more frequently in hematology-oncology than in the intensive care units. One third of physicians (32%), equally in hematology-oncology and the intensive care units, asserted that they firstly inform their decisions on evidence. This information, supplied to parents as “proofs” will guide or should guide their eventual decisions. Finally, 17% of physicians interviewed expressed a patient-centered approach to care (more frequent among intensive care unit physicians). For certain physicians, this approach translates the child’s participation regarding the concerning decisions while for others it shows the importance attributed to the “best interest of the child” which reaches beyond parents’ perspective.

Ultimately, what the parents believe matters little. And it’s difficult, because if they say “no, we don’t want such an intervention.”, therefore we have the obligation to say: “You are not acting in the best interests of your child and we will not let you do this.”

Physician, ICU

Despite the limited scope of these models, (for which a consensual definition does not exist), reference to one approach or another mostly indicates an idealized vision of the social and relational dimensions of clinical encounter. Combined with one or another value actualized in the following or the cessation of treatments (for example), these approaches offer nonetheless a glimpse of these decision-making models, anchored by in the context of practice.

Differential relationship in time: between chronicity and acute

Different hospital units have distinct rhythms, temporalities of treatment, care and decision processes which impact upon the woven threads on clinical relationships.

[...] we really don't have a long-term relationship which leads, like in oncology, to a therapeutic alliance. Actually, a part of the problem is that they must trust us in a short amount of time. We tell them things, their child is very sick, "we are going to stop the treatments," or on the contrary, "we will continue to try to save your child." They have to trust us."

Physician, ICU

The very notion of collaborative decision-making implies that parents and healthcare professionals meet on a time continuum. Some physicians will acknowledge this, others may have greater difficulty.

If they are not ready, we will wait. We won't go against [their will]. We will work daily in order to make them progress. Life is like that. It is hard to hear it the first time [the possibility of withdrawing treatment], but after that, whether they want it or not, they progressively assimilate the information. The parents see their child deteriorate every day, witnessing a lot of suffering and after a moment, they become ready. But others will never be ready. The child is going to die on the ventilator after many weeks like this.

Physician, ICU

However, parents must be included into the decision-making process, which is not always the case.

It is necessary to sit down with the family. [But] it is easier to do everything than to limit the treatments. Ultimately, it is easier not to think about it.

Physician, ICU

Not only do these care contexts lead to different rhythm,⁷ but also to a distinct doctor-patient relationship. A child with cancer will usually be followed by the same physician, throughout the course of his illness (and with multiple consultants). However, in the intensive care unit, this physician, similar to an orchestra conductor may be delayed, or not even come on stage. Consequently, the child and the healthcare professional find themselves on an unmarked path. Decision-making will therefore be inflected, it becomes less of a doctor – patient relationship and more of a healthcare team – patient one. This way of clinical thinking has something to do with the “acute” nature of the circumstances associated with the intensive care unit and the increasing specialization of contemporary biomedicine, and in a corollary manner to the compartmentalization of knowledge. This last point favors the transmission of information rather than sharing of knowledge. In contrast, the patient-family-doctor relationship developed over time in hematology-oncology is often depicted as very different:

Our work is not only to provide care, really, anybody can give chemotherapy. Our work is really to help this family pass through this crisis.

Physician, Hematology-oncology

And indeed, many physicians in oncology expressed this emotional dimension which develops over the course of time.

It is very difficult for us, because we become so emotionally invested to each of our patients. We become a member of the family, because we see them so often [...] Therefore it is very difficult to have ‘this conversation’ with the family, and say “there is no more chemo possible, we can do what is necessary so that she is comfortable, so tell us how you wish the end to happen”. It’s very difficult for us physicians. It is like we are abandoning them, but this is not how we are trained. We are trained to save patients, to do everything to save them. Therefore the emotions we receive [during these conversations], it is very difficult.

Physician, Hematology-oncology

This emotion (and more generally subjectivity) influences decision-making, which cannot be reduced to a “rational” logic (Simon, 1955), often associated with evidence in this particular context of care. This shows the complexity of decision-making as an amalgamation of expert knowledge, experiential knowledge, relational knowledge, in an exchange that is (at best) shared, co-invested, meanwhile remaining unequal.

⁷ In addition to the different pace in the units of care, the encounter with illness leads to very different temporalities for healthcare professionals, for whom illness is their daily reality, and the parents (migrant or non-migrant) who experience this unique situation in a variable life context.

THERAPEUTIC CONTINUITIES AND DISCONTINUITIES

Biomedicine (such as bioethics) is not singular, but multiple (DeVecchio Good, 2007; Finkler, 2008): many ways of approaching a patient, interpreting symptoms, and juggling different therapeutic options. There are numerous examples where, in the same situation, two clinicians will choose different treatments within the same unit, divergent courses of care just such as the withdrawing or restoration of curative treatments, need or futility of a transplant, etc. These divergences can be discussed between clinicians within the team in the hopes of collectively orienting a course of care or can be presented to parents as potential options. This discontinuity in the therapeutic orientation at the heart of the medical team can be a source of perplexity, just as the possible gap between the family members' definitions on the meaning of life, the end of life and the quality of life. A logic of treatments can become antagonistic to a logic of accompaniment (Mol, 2008). These logics are inscribed in ways of viewing the clinic as a meeting place and negotiation or as a place offering services.⁸

The organization of hospital work, and in this precise case, the intensive care unit, is highly effective for situations of acute care. Nevertheless, the patients who are at the same time “acute” and “chronic” (known as acute long term) pose unique challenges, obviously regarding morals and values related to the therapeutic range and the necessity to act, but also on the organizational level. The alternating medical responsibility of patients and an essentially *ad hoc* and variable orchestration of a communication plan with families become sources of confusion and mistrust. This variability is attributed to the rapid or less rapid changes in a child's health status, to the necessity for physicians to consult the parents at critical moments in the care trajectory; and in a certain manner, to the importance accorded by the treating physician to this process. This importance is inseparable from the condition of the patient, but also from local community practices and training. However, informed shared decision-making makes sense only within the optics where information circulate beyond the perspective according to which knowledge and information lead to a rational choice (Rouleau, 2007). And even when information is shared, individuals will make choices in a subjective manner according to their role (parent, clinician and their setting) and their values (Simon, 1955).

⁸ These logics are also embedded in a legal system where, according to local traditions, the clinician will be more or less protected from prosecution. In the United States, for example, these prosecutions are frequent. Paradoxically, the “freedom” of choice (in terms of directing treatments) is widespread across the United States where private healthcare is also widely found.

Two healthcare professionals (intra and interdisciplinary) can envisage differently a care trajectory, just as parents can nourish divergent points of view.

DOES KNOWLEDGE CIRCULATE?

Standards for communication are intimately associated to values. How important is family participation envisioned in the decision making process? Are meetings with families of an *ad hoc* nature or are they scheduled on a regular basis? Are these encounters part of a “best practice” endeavor or are they rather of a voluntary and individual nature – some physicians having regular meetings with families while others less so? In the intensive care units we studied, this communication is not established from the outset, since the patient management is oriented towards immediate response to an acute problem. The building of a relationship with the family, indivisible from the patient, is therefore not a norm of practice. However, medical and technological progress is transforming these units of acute care into units where complex health care issues give rise to extended stays (“the acute chronic”), where consultation with families and the sharing of information becomes essential. Yet, these links remain vulnerable, often fashioned by the clinician in practice. The “Other” is none the less fragile, and without communication, no doctor-patient bond⁹ is possible. This relationship of trust is essential in sharing a decision.

Another structuring element of the doctor-patient relationship, in particular the doctor-patient-family relationship, is the congruencies of biomedical thought. A deviation from this congruence is often explained by profane knowledge associated to culture, religion and misunderstanding of science. When parents tend to diverge too much from what is considered acceptable as an attitude in the therapeutic space, they are identified as problematic or left out of discussions. It is in these circumstances that culture, ethnicity, social class and religion are invoked in order to explain their beliefs or marginal behaviors (Fortin and Carle, 2007). Consequently, the presence of symbolic resources¹⁰ in the clinical space, expressed primarily as a good understanding of their child’s medical condition and mastery of medical language is certainly an asset for parents, for their perception by the team and for following relationships. A prime example is the differential recourse to complex protocols of management of children with cancer. The consent for these protocols

⁹ By symbolic resources, we understand the social recognition of the group to which the patient (and his family) is thought to belong and the value of this position within a given setting (Taboada-Leonetti, 1994).

¹⁰ Our translation of the term « colloque singulier ».

require a very good comprehension of the official public language. As will be evident in the following quotation, (which was collected in a location where 46% of the population is born outside of Canada):

If this is a complex study and parents do not speak the official language, therefore, occasionally we can decide not to choose this particular protocol and go with a standard protocol. We will follow the general idea of the more complex protocol, but with the basic approach. They have to be able to understand the [more specialized] protocol otherwise they are going to have the standard one.

Physician, Hematology-oncology

In hospital settings as in others, these symbolic resources are unequally distributed (Fortin et al., 2011). However, they cannot be reduced to the comprehension of biomedical information and they extend to an entire habitus that, if it is shared, gives an advantage translated here as a communicational flow which makes possible the sharing, and maybe negotiation, of knowledge and decisions to come.

You see, when Dr. X met with us to offer this program of care, he explained that it is not the standard protocol [...] he said that this study here, was presented to parents with a higher level of education, which is our case [...] he told me] that he felt comfortable proposing this protocol given that [...]with] our level of education, we could understand and we could make an informed choice.

Mother of patient hospitalized in hematology-oncology

If parents who are educated or able to understand the transmitted medical information are more involved in decisions, they are also the most “audible”. Their voices will indeed be heard, but they may also become “difficult” families. They can be demanding upon the healthcare team, because they want the best for their child. Certain clinicians view this as a stimulus and begin a dialogue. Others will flee, meetings become less frequent, and the exchange of information is gradually cut short.

According to me, it appears almost as a U-curve, don't you think? When a family is a little difficult, I believe they receive a little more attention. You tell yourself: “I should go to the room and tell them what I am doing, otherwise they will be worried.” At this stage, yes, you give a little more. But when a family becomes a little too demanding, the doctors begin to avoid the room and the nurses postpone giving care. They fear their reactions, they don't want to be yelled at, right?

Physician, hematology-oncology

This shows that if a family is too demanding, they can eventually lose their gains and if a family demands too little, their expectations, needs and values will be ignored.

BETWEEN REASON, SCIENCE AND CULTURE

Do the different rhythms mentioned above coincide with these different models of decision-making repeatedly documented in the intensive care units and oncology? The relationship formed with the patient is not the same. The often intimate knowledge of the therapeutic pathway with the highs and lows over long periods of time, statistical data advanced by oncology on the success of such and such protocol of care, or the observation of the child's suffering in critical situations are all elements that lead to the variability of perspectives in this often ultimate decision-making for the patient and the family. Regardless of the suggestion to maintain or withdraw treatment, in both cases the physicians estimate to base their decision on reason, on an objective reading of the situation. The best for the patient, here, is determined by medical knowledge considered as objective.

Ultimately, one must not forget that our mission, as pediatricians, is to take charge of the child, and that the parents are partners in the project, but if they oppose it, it is absolutely impossible that we consider taking more time to do things. At a given moment, when we see that time can interfere on the quality of care and quality of our patient's future, it is necessary cross out the parents [...] that is also our role as pediatricians.

Physician, Hematology-oncology

What about the parents? If their expectations deviate or oppose the medical decision or suggestion presented to them, this divergence is considered "subjective." Furthermore, when parents are immigrants, this divergence will be attributed to cultural or religious values. In so doing, dichotomously, the welfare of the child is a matter of medical knowledge or one of cultural or religious values, often those belonging to others. And even though, from a sociological point of view, we can agree that both clinicians and parents place values at the forefront at the time of the decision between the end or the pursuit of treatments, the clinician's values will take the form of norms. As stated by one clinician, there comes a moment when it becomes their responsibility (and that of the hospital) to make sure that the parental values do not threaten the child's health:

[...] people can believe what they want and they can live as they see fit in Canada. This is part of our [Canadian] values. But, when these beliefs come into contact with an institution (such as ours), a national institution, they encounter a rigid system, and even though we want to be flexible; in the end we are still pretty rigid.

And I also have a system of values and I don't need to apologize for it. If I can heal a child and the mother doesn't want me to give such or such a therapy, believing that alternative medicine or herbs will heal the child, if I know that it won't work, I must intervene. It is my responsibility in this society to defend the child.

Physician, Hematology-oncology

However, certain clinicians show a particular reflexivity toward this double stance, simultaneously normative and subjective. They question their capacity to transmit information that they consider relevant and at the same time seek to seize what is important for others. This reflexivity does not erase the asymmetry in clinical relationship neither does it reduces the gap between “medical objectivity” and the “patient (and family) subjectivity”, but it may favor the recognition of uncertainty as an actor at the heart of the decision-making process.

At the intensive care unit, we make claims on the quality of life and advance judgments on the value of life in specific situations in accordance with our education. And we presume that the information given [to parents] will be useful in regards to their education. But we don't always know what are their beliefs and their education; therefore it is easy to be mistaken. I know that we make mistakes.

Physician, ICU

BY WAY OF CONCLUSION

The medicalization of health or the classical biomedical approach centered on pathology is often not in conflict with the expectations of migrant families met during the course of this research. In the hospital situations we documented, from birth to the end of life situations, the medicalization and technology of specialized care is viewed as an important resource of the local society. Biomedical knowledge is generally welcomed and little negotiated. When there is a negotiation (without the rejection of the dominant biomedical perspective), a common set of values is put in place in seek of a favorable context where the triad (healthcare professional-patient-family) can evolve. On the contrary, when there is a divergence from biomedical norms, culture and religion become explaining phenomenon, at the expense of a reflection on the sharing of knowledge, and the parents needs formulated are not often heard.

Beyond the migrant/non-migrant aspect, the notion of diversity and of plural society calls for the recognition that all localities are crossed by gender, age, religion, social status, and ethnicity relations historically and political constituted.

Clinicians and families are participants in these settings and carry with them norms and values fashioned by these milieus and individual trajectories. However, unlike the parents and society in general, clinicians can orient the norm towards their own values, in the space of the clinic. In this perspective, Kaufman, (1997) states that there is no clear demarcation between the moral field and the clinic one – the two being intertwined. Whether we talk of a doctor-patient bond or not, the specific relation between the doctor and the patient blurs these boundaries.

Similar to Ricoeur (2001), Payot (2007) insists on trust as the key element in the doctor-patient relationship and decision-making, trust made possible by listening to the other. More than a simple juxtaposition of this dimension to a paternalistic, freedom of choice or shared decision-making model, Payot evokes a trust that is born from recognition of the decision-making potential of the patient/family as knowledge and hopes, contexts and experiences amalgamate in a clinical relationship which is for always asymmetrical. Is this a preamble to an ethics of recognition which admits uncertainty and misreading of the “Other” as part and parcel of the clinical encounter?

Beyond the relational dyad or triad and the qualities of the individuals at hand, the decision-making modalities and values, and even the standards of practice advocated by clinicians are dependent upon structural conditions and the management of units of care. The hospital is a place by excellence where medical knowledge is undisputed. This knowledge is presented as anchored in reason. Yet, the variability documented in daily practices reveals how actors who participate in the clinical encounter are also social and cultural beings. To document decision-making and more generally norms and values in action, is to document the tensions of diversity, a tension that we prefer to silence. This tension may translate, sometimes awkwardly, the search for a balance in this asymmetrical relationship between physicians and their patients, an equilibrium between norms and values, between the individual and the collective.

REFERENCES CITED

- Bouchayer, F., Cresson, G., Penneç, S., & Schweyer, F.-X. (2004). Introduction. In F. Bouchayer, G. Cresson, S. Penneç & F.-X. Schweyer (eds.). *Normes et valeurs dans le champ de la santé* (pp.5-16). Rennes : Éditions ENSP.
- Bourgeault, G. (2004). *Éthiques. Dit et non-dit, contredit, interdit*. Sainte-Foy : Presses de l'Université du Québec.
- Canguilhem, G. (2011[1966]). *Le normal et le pathologique*. Paris : Presses Universitaires de France.
- DelVecchio, M.J. (2007). The Medical Imaginary and the Biomedical Embrace: Subjective Experiences of Clinical Scientists and Patients, in J. Biehl, B. Good, and A. Kleinman (eds), *Subjectivity: Ethnographic Investigations* (pp. 362-380). Berkeley, University of California Press.
- De Vries, R., Turner, L., Orfali, K., & Bosk, C. (2007). Social Science and Bioethics : The Way Forward. In R. De Vries, L. Turner, K. Orfali et C. Bosk (eds.). *The View From Here. Bioethics and the Social Sciences* (pp.1-12). Malden : Blackwell Publishing.
- Edel, M., & Edel. A. (2000). *Anthropology and Ethics : The Quest for Moral Understanding*. New Brunswick, N.J. : Transaction Publishers.
- Fassin, D. (1996). Le pouvoir de guérir. *L'espace politique de la santé. Essai de généalogie* (pp.123-198). Paris : Presses Universitaires de France.
- Finkler, K. (2008). Can Bioethics Be Global and Local, or Must It Be Both? *Journal of Contemporary Ethnography*, 37(2), 155-179.
- Fortin, S., Rietmann, M., & Duclos, V. (2011). Toutes les familles ont-elles une même voix en contexte de soins ? In F. Kanouté & G. Lafortune (dir.), *Familles d'origine immigrante : polysémie des pratiques sociales. Enjeux sociaux, de santé et d'éducation* (pp. 11-28). Montréal : Presses de l'Université de Montréal.
- Fortin, S. & Carle, M.E. (2007). Santé et pluralisme. Vers un nécessaire repositionnement de la culture dans l'espace clinique. *Bulletin de l'ARIC*, 45, 5-19.
- Kaufman, S. (2001). Clinical Narratives and Ethical Dilemmas in Geriatrics. In B. C. Hoffmaster (ed.). *Bioethics in Social Context* (pp.12-38). Philadelphia: Temple University Press.
- Kaufman, S. (1997). Construction and Practice of Medical Responsibility: Dilemmas and Narratives from Geriatrics. *Culture, Medicine and Psychiatry*, 21,1-26.
- Lambek, M. (2010). Introduction. In M. Lambeck, (dir.), *Ordinary Ethics* (pp.1-36), New York: Fordham University Press.
- Le Blanc, G. (2002). Le conflit des médecines. *Esprit*, 284, 71-80.
- Mol, A. (2008). *The Logic of Care. Health and the Problem of Patient Choice*. London & New York : Routledge.
- Paillet, A. (2007). *Sauver la vie, donner la mort. Une sociologie de l'éthique en réanimation néonatale*. Paris : La Dispute.

- Payot, A. (2007). Éthique du processus décisionnel entre parents et néonatalogistes: défis éthiques soulevés par l'exercice de l'autonomie dans des situations aux limites de la viabilité. Thèse de doctorat, Sciences Biomédicales, Université de Montréal.
- Pellegrino, E. D. (1987). The Anatomy of Clinical-Ethical Judgments in Perinatology and Neonatology: A Substantive and Procedural Framework. *Semin Perinatol*, 11(3), 202-209.
- Ricoeur, P. (2001). De la morale à l'éthique et aux éthiques. *Le Juste II* (pp. 55-68). Paris : Esprit.
- Rouleau, L. (2007). *Théories des organisations. Approches classiques contemporaines et de l'avant-garde*. Québec : Presses de l'Université du Québec.
- Simon, H. A. (1955). A Behavioral Model Of Rational Choice. *The Quarterly of Economics*. (69), 129-138.
- Taboada-Leonetti, I. (1994). Intégration et exclusion dans la société duale. Le chômeur et l'immigré. *Revue internationale d'action communautaire – RIAC*, 71, 93-103.