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Dialectics of balanced autonomy in disagreements between patients and surgeons

ABSTRACT

OBJECTIVE: To comprehend different logics of autonomy that are present in conflicts between surgical prescriptions and the expectations of patients with diagnoses of cancer.

METHODOLOGICAL PROCEDURES: This is a qualitative study in which 11 semistructured interviews were conducted with oncological surgeons specializing in head and neck tumors, in the city of Rio de Janeiro, Southeastern Brazil, between 2000 and 2005. The participants were selected by means of chain sampling and the fieldwork was halted in accordance with the criterion of saturation. The discourse analysis technique was used to identify the premises that structured the concept of autonomy and would constitute the discursive dialectics within the context of patients who fight against undergoing surgery that is considered to be of mutilating nature.

ANALYSIS OF RESULTS: At first, the surgeons expressed standardized statements centered on deontological concepts of autonomy. As they narrated their experiences, self-questioning that brought out contradictions regarding the routine concept of "informed resectability" was observed. At this point, the standardized discourse became permeated by self-questioning about the need to return to the existential balance that had been harmed by the cancer.

CONCLUSIONS: The narratives expressed demands for "balanced autonomy" in the form of a semi-project that is not aprioristically idealizable but is dependent on mutual interactions. The results indicated the need for reflection on the concept of autonomy as a linear, categorical and individual premise that, although superficially elaborated, governs everyday actions.

DESCRIPTORS: Physician-Patient Relations, ethics. Treatment Refusal, ethics. Treatment Refusal, psychology. Patients, psychology. Neoplasms, surgery. Communication Barriers. Paternalism. Ethics, Medical. Qualitative Research.

INTRODUCTION

Over recent decades, cancerology has become a complex and interesting field of activity for various professional groups. However, the debate on the ethical presuppositions that inform its interventions has not expanded in line with the increasing technical sophistication.[17] Within this field, bioethics has added interesting debates about the constituent elements of patients' autonomy[5,14] and the need to acquire communication skills regarding adverse prognoses.[2,a]

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[a] Buckman R, Baile W, Korsch B. A practical guide to communication skills in clinical practice [CD-ROM]. Mississauga: Medical Audio-Visual Communications Inc; 1998.

Within the field of oncological surgery, even though tumor staging is currently the main determinant for the therapeutic approach, there are various ethically important demands that are still not considered in decision-making.[12,13,20] The model of individualistic autonomy centered solely on decisions informed by patients has been questioned. This model does not have room for contexts in which the relational and dialogic aspects of this principle should gain strength.[5,10]

Even though the impact of interventions has diminished over recent decades, head and neck surgery still bequeaths unavoidable sequelae that are sometimes more mutilating than the initial staging of the disease was, with traces of moral and physical distress. Tragic diagnoses and interventions in these contexts tend to generate intense emotional pressures of varying origins and defense counter-mechanisms.[27] Supplementary tensions are generated by the technical imperative to demand immediate actions in contexts that sometimes present conflicts of opinions between surgeons and patients. Such contexts lead the professionals in question to deal routinely with physical and moral suffering under the condition of vulnerability that results from diagnoses of cancer.[a]

The objective of the present study was to understand different logics of autonomy that are present in conflicts between surgical prescriptions and the expectations of patients diagnosed with cancer.

METHODOLOGICAL PROCEDURES

A qualitative study was carried out, in which 11 semi-structured interviews were conducted with oncological surgeons specializing in head and neck tumors in the city of Rio de Janeiro, Southeastern Brazil, from 2000 to 2005. These surgeons worked in both the public and the private sector and were selected for the interviews by means of mutual recommendation or chain sampling.[19] Among other matters, it was sought to identify the discursive dialectics involved in the decisions relation to patients who refused to undergo surgical interventions. During the pilot phase, five interviews were held. From the first readings of the material obtained, these interviews guided the selection of the second group of six interviews, which contained an expanded list of questions. The interviews began by dealing with the daily routine of the diagnostic-therapeutic process in order to direct the questions towards cases of conflict between the technical perspectives and the clientele's perspectives. The main topics in the guidelines for the interviews were the following: qualifications and length of practical experience; diagnosis-staging process and indications for intervention; cases that are considered difficult; extreme situations (such as refusal to undergo the indicated surgery); perceived dilemmas; and communication of adverse prognoses.

The data collection was halted in accordance with the criterion of "exhaustion" or "saturation" of the study subject within the set of material.[24] Within the discursive scenarios, it was sought to delineate the structuring premises and rationalizations of the dialectic process involved in the concept of autonomy that usually guides surgical decisions.[25]

To analyze the material, after transcribing the text and checking its faithfulness, it was firstly read in a flowing manner[2] (first contact from which preliminary guiding impressions emerged). Next, it was read for "impregnation", i.e. in-depth reading of each of the reports, to seek to understand the whole of each testimony.[27] Based on this reading and discussion of the preliminary texts, a strategy for subsequent approaches could be drawn up. From this, a provisional interpretation scheme emerged (synthesis of each testimony), to guide the category analysis.

After producing the provisional syntheses, in which the focus was the singularity of the concept of autonomy in each interview, horizontal reading of the set of reports was undertaken. This allowed us to identify a system of relationships and secondary categories. In this way, it was sought to pick up the relationships that were constructed discursively between the moral subjects and their discourse and practice.

The theoretical approach used was Habermas' concept[7,22] of tension between instrumental rationality (linked to the sphere of work and production) and communicative rationality, which identifies and reconstructs the universal conditions of the understanding that is possible, centered on the use of language.

This project was approved by the Research Ethics Committee of the *Fundação Oswaldo Cruz*. In conformity with Resolution No. 196/96, the participants signed a free and informed consent statement that contained the objectives of the study, the assurance of anonymity and the researchers' address.

ANALYSIS OF THE RESULTS AND DISCUSSION

Without exception, the receptivity and availability of the interviewees was considered very good, in the light of the difficulties brought up by this topic. Some interviewees expressed themselves in a more formal and assertive style, while others formulated their uneasiness as self-reported questions. There was perceptible frankness and interest from most of the interviewees and they often clearly revealed personal traits, which have been omitted from this paper.

[a] Cestari MEW. A influência da cultura no comportamento de prevenção do câncer [master's dissertation]. Londrina: Programa Interinstitucional da USP, UEL e UNOPAR; 2005.

The structuring premises that were identified were explored, thereby making it possible to foresee dialectics of complementariness between the imperatives of instrumental intervention and communicative action. The conversations went beyond the initial pronouncements, based on stabilized notions around the activity in question. The focus of interest was concentrated on strategies for reaching agreement in the light of dissension, which was frequently connected with ethical unease relating to the concept of autonomy.

At the start of the interviews, in descriptions of the decision-making process (and identification of the mechanisms for arguing in defense of the perspectives of beneficence and autonomy), what emerged most prominently was "standardized discourse". The pronouncements were repeated almost in the same words, without critical or self-critical intentions, and always supported either by instrumental strategies (centered solely on objectivation of cancers to be resected) or by deontological discourse regarding autonomy. These were interpreted as "algorithmic discourse" (emphasis on the complexity of dealing with fragile structures surrounded by tumors that are difficult to delimit), in describing a type of decision-making protocol that does away with evaluation of the non-material effects from the intervention on personal expectations.

The impact of the interventions around the "target tissue" was dealt with very little, and no preoccupations were expressed regarding what had happened, in relation to the patients' lives in the past and in the future. The standard discourse gave little consideration for the plural needs for overcoming the challenges in the patients' futures. Under the weight and urgency of the surgical demands, it became impossible to attend to the existential pressures generated under such conditions. Within this context, the sense of heroic rescue was the tonic for the intervention: well-directed separation between what was and what was not cancer. The patients' biographies, and the idea of autonomy that opposed the "self-evident" benefit from the resection, were almost obstacles to instrumental action. The tools needed for deliberations seemed to be limited only to the diagnostic arsenal that delimited the resectable margins of the tumor.

"To have a very good idea of the larynx before operating on the patient… This is the examination part, and then the imaging part comes; you need to have a very good idea of radiology... Nowadays, with magnetic resonance and computed tomography: without one of these examinations, most head and neck tumors would not have a correct diagnosis. So, you... have to get these examinations done if you want to make good decisions about what you are going to do with the patient." (interview 3)

"Surgery is delicate and... you have to evaluate whether the tumor is resectable or not, very carefully, because there are a lot of prime structures, a lot of nerve structures." (interview 2)

On the other hand, this homogeneity in the testimonies was not seen in relation to the conflicts generated through disagreements. Sometimes, "deontological discourse" was adopted, in which discordant decisions were simply accepted without actively seeking interlocution and counter-argument, at the cost of limited logic of "informed resectability". In such cases, the professionals seemed to presume that the alternative choices were guided by adequate information about the risks and consequences, without considering the differences that were sometimes imposed by low educational levels and states of extreme commotion.

"Now, whether he wants the treatment or not – this is the way I see it – it's entirely his problem. If he refuses the treatment, my role is to lay out, in the best way possible, what can be done for him; what will happen to him if has the treatment and if he doesn't, and to try to make him understand this. Now, if he doesn't want to be treated, this is the role of patient choice." (interview 7)

"The guidance given is not to regard this position of the patient as a form of contestation of what is indicated, but rather, as a personal point of view for which there are reasons that need to be respected. Our job in this case will be to offer this patient, from among the remaining options that we have, the one that is best and most appropriate for him… This tendency really exists, doesn't it? When the patient doesn't do what you say, there's a tendency for professionals, surgeons, to distance themselves from the patient, especially when you've recommended surgery and the patient doesn't accept it." (interview 1)

As the conversations developed, a type of "attenuation" of the technical emphasis of the discourse was perceived. Initially, there was a deontological-instrumental discourse that can be summarized as the duty to inform and to accept either acquiescence or desistance: always, and inadvertently, starting from markedly asymmetrical perspectives. Subsequently, indications of unease were observed, particularly in relation to the inherent limitations of surgical techniques for rebalancing the daily lives of individuals affected by cancer. Although the tonic was still the "heroic rescue", it was noted that there was concern regarding reestablishment of speech functions, deglutition and acceptable esthetics. Sometimes, the interviewees described how they used tactics in their approach that sought symmetry in order to stimulate dialogue, with a view to coordinating the actions.

Thus, the purpose of the intervention ceased to be separation of the malignity from the sound tissue and there was a subtle change in focus towards reestablishing

organ functionality within the context of a fully acceptable life. This may have expressed the (unconfessed) need for reflection that was less superficial in nature, regarding the concept of autonomy as a categorical, linear and unconditional directive. Although such premises were weakly grounded, they governed the day-to-day actions. Going beyond the deontological-instrumental discourse, the technical assertions were permeated by the intention to seek dialogue through harmonization, to lead patients back to a balanced and functional life with minimal sequelae. Although the notion of resectability was initially seen to be markedly part of the conversations, through a large amount of standardized discourse, other values and premises came to light in particular ways.

The interviewees presented reflections of greater or lesser explicitness that showed concern for the quality of post-treatment survival. This gave rise ultimately to discourse on balanced autonomy, guided by the notion of a "return path".

"You can't just judge the cancer. You have to judge the disease with the patient… All our operations will have consequences and sequelae that are going to change patients' lives, together, aren't they? … There's no point in treating the cancer if you destroy the possibility for this patient to have quality of life afterwards." (interview 4)

"I try to make it as explicit as possible, about what's going to happen to him... whether he will feel pain… whether he will have difficulty in eating; whether he will feel breathless; whether he will have bleeding... While most people try to hide this and leave everything for the psychologist, I try to give the patient some idea of what's going to happen to him from now on." (interview 8)

"You're going to reconstruct; you're going to make flaps; you're going to bring him back. So, you have a very big exchange in the treatment... From curing the disease, from reestablishing function and, at the same time, giving a satisfactory result to the patient. So, I think that this integration between all these factors really makes this specialty attractive." (interview 4)

The operability to restore the existential balance that was taken away by the disease goes beyond the mere resectability of the tumor. For interventions to be successful and correct, there has to be an organic and psychological system surrounding the surgical field that provides ideal conditions for virtuous surgical techniques. From this perspective, the conditions of the return to an acceptable social life that includes companionship with family members and friends are brought into play.

"And for him, it [the surgery] was a benefit… The people who he lives with, his companions, are people who accept this well, and there hasn't been any discrimination or any ill will about what was done… He was going to have a very sad death, if the tumor had been left the way it was… It's good sense. And how am I going to get this good sense?… Only through experience." (interview 4)

Organic-existential rebalancing was the aspiration, with little stigmatization and with a quality of life that had not been envisaged previously but which can be gained in the light of personal perspectives. At this point, going beyond mastery within the technical sphere, the surgeons started to show interest in communicative action as an intermediary for attaining an acceptable project and autonomy of survival. As the conversations evolved, the dialectics of the discourse revealed convergences and divergences regarding informed resectability. Sometimes they took on the role of a tutor, sometimes the role of a counselor and sometimes even presenting paradoxes capable of rich interpretations. These same professionals who earlier had described attitudes of keeping a distance in their practices started to show that they felt aggrieved about the lack of space for interaction where they could offer much more than their surgical expertise.

"The time we have is very short: I can't spend an hour talking to the patient... I do what's possible within five or ten minutes, which is the time I have for each consultation." (interview 8)

"We do so many operations that it drives us mad. There are a lot of patients with advanced cancer... With recurrence, because they have advanced cancer, don't they? So, it's a complicated situation." (interview 3)

It seems that not much room remains for communicative action in this type of activity within the scope of the public healthcare system. The surgical-instrumental discourse relating to the vulnerability of sick patients is insufficiently mature for self-critically responding to questions about such way of attending to the clientele. On the other hand, ideals for rebalance and not just for resection were also observed. There was also an aspiration towards a "return":

"Didn't I get this patient to have the treatment? And didn't I really… Did I really provide a benefit? This man still had neurological sequelae… He had a defect on one side of his face… But he's living in the South; he comes here every four months; and he's eating normally... He's there with his family. He has this mutilation on his face, but… What choice was there for him? None. If he hadn't had this surgery, he would have died… But even so, with this life he's leading now, if he'd known beforehand, would he have agreed?… I think that he might have, because he's still with his family. So, it's not enough for you just to see the patient in isolation; you have to see the patient as a whole, with the setting that he lives in." (interview 8)

Thus, the disease acquires the features of an existential condition: a challenge to be overcome that requires not only an effective instrument but also reflection on the role of the physician in the light of human finiteness. Balanced autonomy arises in the form of a semi-project that cannot be aprioristically idealized but is always dependent on experiences of otherness.

Exclusive power to act in relation to making crucial and often irreversible decisions is vested in individuals who are capable and informed. Nonetheless, with these perspectives in the context of a democratic, pluralistic and secular society in which differences are semi-malleable, a utopia would be created, with establishment of "ethical measurement", an irreducible and universal mark of autonomy.[11] The unease originating from such obstacles lead some people to perspectives of greater skepticism: unviable bioethics that embraces the peculiarities of the billions of moral agents inhabiting the planet.[3]

Biological and technoscientific advances are adding unknown questions to a complex sociocultural context of reaffirmation of individuals' moral responsibility to put their existential pathways as the starting point for the physician-patient relationship.[a] The canonical Hippocratic principles of the medical ethos no longer serve to mediate analyses or resolve emerging moral conflicts.[a] The light of a concept of autonomy that is accessible to clinical contexts like the one described here escapes from us, given that the existing concept is theoretically complex and difficult to apply in practice.[21]

On the other hand, the peculiar hierarchy of values that governs decision-making in medicine is considered by some people to be a collective defense against anxieties that result from the occupation and from constantly dealing with situations of impotence.[4] In particular, surgeons are persistently challenged by the existential realities of their patients.[23] Because of the limits imposed on instrumental action, a refined sense of ethics that goes beyond technical expertise is required. There are situations in which agents feel under pressure to choose between several approaches, due to moral tensions.[23] Although such decisions are facilitated by technical imperatives, they are inclined towards protocols and algorithms. In the scenario described here, such tensions were not presented as explicitly as questions relating to the success of technical implementations, given that alternative approaches that conflict with stances of greater distancing are tacit and constantly overcome.

Nonetheless, as the dialogic space between the professionals and interviewers expanded, it was perceived that the inflexible itinerary of technical thought and action was left permeated with questioning and reflections about balance, delineated exclusively by the illocutionary force (with variable emphasis and elaboration) of the dialogues.

The seeds of the paternalistic bad habits that have found fertile soil in the public healthcare system germinate through superficial reading of the scenarios described here. At the confluence of the technical demands (for production and speed of attendance) with the communicative demands of a clientele that has received incomplete explanations about the nature and prognosis of its problems, the players tend to make tacit agreements. It is certainly possible to imagine that, at the most condemnable extremes, such agreements might be based on a condition of special vulnerability, in which the clientele tends to acquiesce in all decisions and to resign itself to trust the specialists almost unconditionally. Such trust, if barely questioned by either party, gives rise to the semi-paternalistic category of autonomy for acquiescence. With the security of deontological-instrumental perspectives, resorting to the other party merely for acquiescence or dissent, tumor resection alone can be taken to be the idealized beneficial purpose. However, it must be recognized that involvement with individuals whose expectations for survival are poor implies unsustainable psychological overload. This tends to cause sublimation in resorting to techniques and alienation of interactions.

Communicative perspectives such as those of "discourse ethics"[9] should be brought in here. These are supported through sharing between subjects in order to identify values and define priorities. Emphasis on interactions between the subjects for them to consider the issues seems to be unfeasible in the light of such asymmetry between the specialists and their clientele. The urgent pace of the contexts described here seems to overload the technical protocols with uncertainties and postponements.

Descriptive studies focusing on medical-surgical rationality or ethicalness seem to choose to typify this from stable and static perspectives. This tends to strengthen the idea of a kind of inherent "essentialness" of the occupation in question.[18,23] On the other hand, an approach considering discursive characteristics that are apparently contradictory can be chosen. This may finish a dialectic that would be difficult to ignore, at the cost of the risk of congealment of the analysis, which would be counterproductive for this stability. The question opened up by the present study is whether different versions would be developed in the dialectic clash between "deontological-instrumental discourse" and "rebalancing discourse"; and whether there would be a search for effectiveness, for swift acquiescence with resectability (selected as the greatest technical

[a] Almeida JLT. Respeito à autonomia do paciente e consentimento livre e esclarecido: uma abordagem principialista da relação médico-paciente [doctoral thesis]. Escola Nacional de Saúde Pública da Fiocruz; 1999.

benefit), through the intermediary of deontological-instrumental discourse. As reflections are introduced through persistent contradictions, questions from which it would be difficult to escape without existential confrontations emerge. Within the deontological-instrumental discourse, would there be any type of conflict between the patient's records of adversity and the professional self?

We do not wish to provoke demolition of professional deontology through this, but to lead towards reflection and questioning of its stabilized uses in medical institutions. From an anthropological point of view, the relevance of the directive nature of the norms,[15,16] alongside the social players' belief in the possibility that they can be justified,[6] may be taken as the main attributes of ethical life. However, it is illustrative to view the paradigm of the philosophies of conscience and the principlist ethics of rationality rooted exclusively in the subject, from another angle. This has shown us that the focus of intersubjectivity is a source of norms, cognition and action.[8]

FINAL CONSIDERATIONS

The decentralization of reason provides conditions for intercomprehension through the intermediary of "discourse ethics": expansion of the pragmatic presuppositions of language through the fields of subjectivity and communication. The multiplicity of contemporary interpretative perspectives should no longer be exhausted through monologic reflections such as canonical definitions of autonomy, which are perhaps insufficient within contexts in which legitimacy and equity occupy center stage. The dialectics of the discourse described here finish the recursive lack of distinction between the potential and limits of instrumental reason, in relation to the demands originating from lapses in communication. Paternalism fueled by lack of dialogue may take on multiple facets, among which the additional speed of attendance may compensate for the narrower and more essential interactions. This tends to originate a normative and minimized concept of autonomy that is confined to informed consent. In this, technical imperatives determine actions that not only are questionable when read more deeply, but also often degenerate into distancing.

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