Challenges of Communication in a Context of Crisis

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Troubles, Misunderstandings and Discords

Edited by

José Manuel Resende,
Alexandre Cotovio Martins,
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INTRODUCTION

A LANDSCAPE OF RESEARCH: SOME NOTES ON THE CONSTITUTION OF A PRAGMATIC SOCIOLOGY AGENDA

JOSÉ MANUEL RESENDE AND ALEXANDRE COTOVIO MARTINS

Although this is an international book, in the sense that its authors, as well as its theoretical frames of reference, are themselves international, we think that this is a good opportunity to address some very basic issues about the process of practicing sociology through the ‘pragmatic’ reference frame in the country of some of its editors, Portugal. As a matter of fact, the works which are integrated in this volume are inspired by the plural theoretical framework of pragmatic sociology and are inserted in the dynamic of research which began at CICS.NOVA-Interdisciplinary Center of Social Sciences – *Making, unmaking and remaking the common in the plural in modern sociality: controversies, recognition and vulnerabilities* –, more than a decade ago, with the work of José Resende, strongly inspired in the work of Luc Boltanski and Laurent Thévenot and, more recently, especially by the work of the latter author. Researchers in this group – the collective named *Pragmaticus* – have been producing research about various themes – from education to health care, from political socialization to professional demands, from public controversies to proximity regimes of engagement –, which we will not try to synthesize here. Nevertheless, we would like to say some very brief words about the work which has been (and is) being made, namely trying to identify some challenges which pragmatic sociology leaves us and, also, to Portuguese sociology and Portuguese sociologists as whole, challenges which we think the researchers in this collective, our research group, try to integrate in their research processes. Of course, what is about to be said has no intent of being thorough or exhaustive.

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About this issue, we would say that the relevance of pragmatic sociology in the Portuguese ‘sociological landscape’ which has being somewhat revealed to us by mobilizing it to develop research, lies in at least two points: its innovative character and its sociological fertility.

i) In the first place, pragmatic sociology represents an innovative approach in the frame of sociological reasoning in our country, since: Portuguese sociology has been constructed around what Fernando Luís Machado, in his article “Half a century of sociological research in Portugal” (Machado, 2009), calls two great ‘institutional generators’: the socio-cultural generator and the socio-political generator. In the former, we have as leading institutions CIES-ISCTE and ICS-UL, as well as other institutions, such as CICS.NOVA and IS-FLUP; in the ladder, we have as leading institutions CES-UC and CICS-UM. According to F. Luís Machado, the epistemic and methodological orientation of the socio-cultural generator is rationalistic, with strong articulation between theory and empirical research; the main international references are Pierre Bourdieu and Anthony Giddens; as to the socio-political generator, the epistemic and methodological orientation is post-modern critical theory, with strong articulation between theory and political doctrines; its main international references are the School of Frankfurt, Immanuel Wallerstein or Ulrich Beck. Our purpose is to develop a political sociology of Portuguese society.
   a) Pragmatic sociology provides an analytical framework which allows us to upset what we would like call this ‘institutional frame’ in Portuguese sociology, opening field to new objects and fields of analysis, new issues, new forms of perceiving and working analytically social beings. Our purpose is to develop a political sociology of Portuguese sociality within the framework of the general program referred to above.

ii) In the second place, pragmatic sociology introduces an extremely fruitful and productive approach to social phenomena which characterize Portuguese’s sociality formation:
   a) Pragmatic sociology induces us to deepen our understanding of human action and coordination, having always as questioning axis the one which stems from what we think is a fundamental finding of this approach: the internal complexity or, more strictly

speaking, the internal plurality of human action, with its multiple, although limited, regimes of engagement; with its complex architecture of internal relations, more peaceful or tensional according to different situations; with its ambiguities and polarities between guarantees and doubts or uncertainty in social situations; with the mobilization of different grammars in action, namely in order to reduce tensions in social settings; with its movements from proximity to generality.

b) Also, pragmatic sociology invites us to take society and ‘the social’, not for granted, but as problematic issues. With this analytical framework, society is not a self-evident, explanatory variable, as in other sociological approaches, which seem to first reify the social to, then, use it as explanatory and determinant to any observable behavior. On the contrary, pragmatic sociology, taking society and ‘the social’ as problematic issues, instigates us to seize the sometimes very delicate movements by which social actors manufacture the common in plural forms, the ways by which they, supporting themselves in the result of past and current investments in forms (Thévenot, 1986), try to build commonality in a rather complex, fluid social world.

c) Pragmatic sociology leads us to take in account objects in human action: the ways by which a regime of engagement involves not only an interaction between human beings in a kind of ‘physical vacuum’, but also, and sharply, the close interaction between human beings and their physical environment, and the ways by which they engage objects in their individual and collective actions.

d) The attention which pragmatic sociology dedicates to the forms of qualification of beings, whether they are human or non-human, also challenges us to take very seriously in our work as sociologists the ways by which cognition is supported by forms of understanding which are built in complex frames of action and which result from different regimes of engagement. In these complex frameworks of action, it is important to highlight the forms of coordination of action and its multiple consequences. Among its possible effects, we highlight the possible critical operations of the subjects submitted to the orientations out of the investments as a result of actions’ coordination. However, if there are critical operations, there may also be situations where criticisms are suspended. In this sense, our regard is attentive to all these possible combinations. Following the actors forces observers to a small-scale craft.

e) Finally, we would like to highlight the methodological relevance of a principle which pragmatic sociology tends to persuit, which is to follow social actors and take seriously their own view of their actions. This principle, here presented in this metaphorical form, challenges us to think in new methodological approaches to sociological objects and, on the other hand, to mobilize strategies which can lead us to take a big, deep dive in the terrains of research, striving to think through fieldwork in the pathway to a better understanding of human action in social settings. Handcrafting of observation work is a crucial point. Ethnographic immersions in different research contexts, informal conversations with actors involved in object-related occurrences, semi-directive interviews, the use of photography and videos, the detailed transcription of the scenarios where the actors interact with each other, are all moments which are part of making sociological science in a crafted way.

As we started to highlight, we didn’t intend to be exhaustive on this issue. We are just trying to pinpoint and highlight some aspects of pragmatic sociology which we modestly think are, and can do it even much more, challenging the usual way of practicing sociology in our country. Doing so, we were trying to introduce, in a way, the following texts, which certainly will be much more enlightening about these and so many other issues than we could be.

PART I:

PROBLEMATIC ASSESSMENTS, INSUFFICIENT MEASURES

CHAPTER ONE

THE DELICATE COMPOSITION OF COMMONALITY IN PALLIATIVE CARE: BETWEEN CRITICAL MOMENTS AND INVESTED FORMS

ALEXANDRE COTOVIO MARTINS

Diversity, Dying Trajectories and Invested Forms in Palliative Care

In the present article, we develop a pragmatic analysis of the processes of investment in forms (Thévenot, 1986; 2006) put into place by palliative care professionals in order to reduce uncertainty and appease disquietude and discord among relevant actors (the patients and their families) in end-of-life situations in the frame of palliative care. In this path, we will highlight the place attributed by these professionals to the patient’s body in the prevention of discord among these actors. Namely, as an *object* over which investments in form can be made in order to guarantee minimal cognitive communalization in end-of life situations, which may be suitable to reduce diversity of representations, and, consequently, uncertainty, disquietude and discord between relevant actors.

In a pragmatic sociology approach, as it is defined by Laurent Thévenot (1998, 2006), one can study cognition by disassembling the concept of *representation*, in order not to take cognition in social settings and in collective actions for granted. As the matter of fact, focusing more on the *operations of representation* than in representations themselves, Laurent Thévenot undertakes an analysis of three kinds of cognitive operations: (i) the process of representing as a cognitive operation of binding different beings; (ii) the process of representing as a political operation of ordination; and (iii) the process of representing as an instrumental operation of putting into forms. In this article, we are interested only in processes of class i) and iii).

Actually, we are trying to study the processes of defining dying or end-of-life trajectories by palliative care professionals, treating these trajectories as social forms suitable to reduce uncertainty, disquietude and discord in palliative care situations. In order to do so, we must pay special attention to the operations of binding material and cognitive elements which constitute the basis for the process of defining dying trajectories. On the other hand, we are trying to grasp the instrumental purposes according to which professionals define these trajectories and the kind of material support they use to give some *objectivity* to these invested forms. Indeed, pragmatic sociology enables us to study the degrees to which a given invested form is *objective*, which, in the view of Laurent Thévenot, is the same to say that we can examine to which degree a form has spatial validity (which the author connects to the boundaries demarcating the community within which a given form will be valid) (Thévenot, 2009a), temporal validity (the temporal extension of the form) and solidity (or, in other words, the extent to which it has "material equipment" attached to it) (Thévenot, 2006; 2009a).

In our previous research (Martins, 2015), we analyzed the specific challenges to which health care professionals are confronted with when dealing with patients and their families in palliative care. We verified that, in these situations, patients and their families and members of the healthcare teams will probably have different experiences in their relation with disease, the organisation of care and end-of-life trajectories (Glaser and Strauss, 2007), whose confrontation at the level of situated action often induces the emergence of troubles in the processes that occur in the daily activities (Martins, 2015). Namely, we found that professionals tend to believe that this diversity affects the comfort of people at the end of their lives, as it tends to bring uncertainty, disquietude and discord around the definition and management of end-of-life and care trajectories (Martins, 2015).

We treated, then, the dying trajectories of patients (Glaser and Strauss, 2007; Martins, 2015) as being characterized by its close relation to critical moments in the frame of specific situations in palliative care. We defined a *critical moment* as a situation where we verified that there is discord between relevant actors in view of elements of uncertainty present in situations of palliative internment. The use of the term 'critical' derives precisely from the nature of these situations, mobilising the critical competences and skills of social actors, aimed at reducing the uncertainty inscribed in these very situations and involving disquietude and discord about dying trajectories. We identified three types of situations with these characteristics within the organization of care and end-of-life trajectories: a) the initial entry and reception into palliative internment wards, provided by healthcare professionals to the patients and their families; b) situations of discussion of the (im)possible hospital discharge of patients under palliative care; and c) situations of discussion of end-of-life trajectories of patients and related aspects. We observed that divergence not only tends to arise in specific situations, but also takes on a variety of social configurations, as we discussed elsewhere about discord in palliative care (Martins, 2015).

We found that a central aspect to be considered in this frame is thus the definition of the dying trajectories (Glaser and Strauss, 2007) of terminally ill patients by professionals, namely in situations in which its objectivity is put to a test. Dying trajectories are defined in a close relation between observable physiological changes in the patient's body and actor's perception and reasoning over them (Glaser and Strauss, 2007). In this text, we treat the processes of binding material objects (as the body of the patient and the specific devices built and used to observe it) with cognitions and the tentative stabilization of these binding processes in a somewhat consolidated form as a definition of dying or end-of-life trajectories. In short, we analyze end-of-life trajectories as invested forms. This, in turn, allows us to question not only the modes by which professionals engage, in their daily activities, in processes of investment in these forms, but also to ask about the degree to which these forms are *objective*, that is, the degree to which they have spatial and temporal validity and solidity (material equipment).

Methodology

Data Collection

The analysis conducted herein was carried out on data collected under the project *Building paths towards death: an analysis of everyday work in palliative care*, reference PTDC/CS-SOC/119621/2010, financed by the Portuguese Foundation for Science and Technology (FCT); in particular the data obtained through twelve months of ethnographic observation carried out at two hospital internment units providing palliative care in Mainland Portugal and 37 in-depth interviews to professionals in palliative care – physicians, nurses and social workers. The ethnographic observation records were kept in 'field logs', drawn up by two scholarship students contracted under the aforesaid project. Data collection occurred between June 2012 and September 2013.

Research Design

Our goal was to make a deep data-collection, in three phases: in the first one, through direct, non-systematic observation and exploratory interviews; in the second one, through ethnographic observation and in the third one, through in-depth interviews. Our population was constituted by professionals of medicine, nursing and social work in palliative care. We chose these professions because (i) professionals of each one of them work directly and in proximity with dying patients and their families; and (ii) they were the most frequent professions in palliative care teams in Portugal at the time of the research. Our sample was constituted by the professionals working in palliative care in the chosen hospitals at the time of the fieldwork process. Fieldwork was to be accomplished in two hospitals with socially contrastive publics. Hospitals were thus selected according to two criteria: (p) the palliative care team of each one of them must integrate the different professions which were to be observed; (q) they had socially contrastive publics.

The data contained in the field logs and interviews were, in the first stage, subject to an exploratory Categorical Content Analysis, based on the following positive discrimination criteria: (i) the existence of relevant family relations (i.e. with observable influence in the contexts of action in palliative care) of patients under palliative hospital internment; and (ii) the existence of discord between relevant actors (patient, family, professionals) in view of elements of uncertainty present in situations of palliative internment. With this procedure, 59 households were identified as being involved in situations with the intended features.

Critical Moments of Discord and *Information*

In our research, we gathered data which unveil the fact that in palliative care, professionals are directly involved in the definition and management of situations of discord, which tend to increase the difficulty experienced by these professionals in approaching what they think to be the ‘social dimension’ of their daily work. We found that a significant part of the situations of discord takes place when there is a diversity of perceptions, expectations and solidity of forms around the definition of end-of-life trajectories; this diversity tends to engage actors in the building of different expected procedures of care, which is the same to say that it tends to create discord over what *should* be the patient’s future procedures of care. For instance, if the patient is to be defined as a terminally ill patient or not, if s/he should or should not stay at the hospital ward, given his/her physical condition, or instead go home with his/her family, or even if s/he is going to die in a short term of not.

One of these ordinary situations takes place when patients are admitted in the palliative care ward. The perception of professionals of palliative care about this is that many of the situations of disquietude and discord between them and the patients, between them and the patient's families, or even between patients and their families, are related to what they consider to be a *lack of information* (of the patient, of his/her relatives) over the patients' condition. In their view, healthcare professionals in other hospital services (as for instance oncology wards, one of the major contributors in number of patients to most palliative care units) don't always say to the patients in what 'real' physical condition they are and don't define in a clear way what is to be expected in the near future. This tends, in their view, to create a lot of turbulence in the admission processes.

> "[The patients] were operated on, the doctor said that it was okay that he would live for the rest of his life and then he or she comes to the palliative care unit and then we have to work all this and that is where it becomes complicated, '- Look – we say –, your doctor, who operated you, told you that at that specific time, but unfortunately the disease has appeared again and has progressed and it's like this...' '- Ah! But the doctor said he'd be fine for the rest of his life. Why is he here?', the family says. And that makes all things a lot more difficult, because the family and the patient are not prepared, and they often react very badly... both being sad or really don't wanting to believe what we're saying.
>
> Sometimes families resist, despite the information we give them, sometimes they pretty much deny the situation. And sometimes they also think they do not need it, they do not need a certain intervention... Because they are not facing this need at the moment [...], but we have to deal with it in advance. And sometimes it is difficult to work with families at this level, even in palliative care. Because people always find that they can, somehow, deny things."

Investing in Forms to Reduce Uncertainty and Appease Disquietude and Discord

Information and Investment in Forms

The specific cognitive forms to which professionals call *information* about the health condition of patients and which they try to manage in their relations with patients and their families are conceptual blends (Hutchins, 2005; Chandrasekharan and Nersessian, 2011) which use is rooted in their daily activity. This *information* is constitutive of prospective dying trajectories which health staff defines, basing this definition mostly in medical knowledge. We call these *medically-defined* dying trajectories. From this standpoint, medically-designed dying trajectories can be analyzed as invested forms that result from the mobilization of complex sets of cognitive forms and its supporting devices, which articulate medical concepts (right away concepts such as 'signs' and 'symptoms', but also complex definitions of organic disorders, etc.), scientific data collected through medical and technological mediations (such as CTs, PETs, MRIs, X-Rays, blood samples, etc.), statistical data about survival rates, etc., and probably, in the most relevant cases, the *body* of the patient, as a material object in which specific medical concepts find root and cognitive support (Hutchins, 2005) and which physiological evolution is the very basis for the definition of dying trajectories and reasoning about them by professionals.

Nevertheless, the definition of dying trajectories in palliative care is not left only to professionals (Glaser and Strauss, 2007). There is quite a diversity in the definition of dying trajectories in palliative care units, namely because different actors bring to the core of these processes different experiences in their relation to end-of-life care (Glaser and Strauss, 2007; Martins, 2015). Given the fact that dying trajectories are not exclusively defined by professionals, the perceptions and expectations of the actors at play, with their specific and differentiated frames of reference developed over time, promote this diversity. This means that the *objectivity* of medically-defined end-of-life trajectories is put to test by these confrontations of diversity. But precisely, the confrontations of diversity are considered to be a problem by healthcare professionals in the palliative care wards that we observed. Not the diversity in itself, but the uncertainty that they believe it can cause, because it is directly related with expectations which, in their view, can create situations of disquietude, discord and consequent suffering to patients.

Believing that informing the patients and their families about their 'real' end-of-life trajectories is the right way to avoid both uncertainty and discord and some forms of suffering related to it, the observed professionals typically engage in a search to 'advise' these actors about medically-designed trajectories. The process, on the other hand, involves communalizing part of the cognitive forms that professionals use among them with patients and their families, be it by means of a sort of 'lay translation' made by professionals *ad hoc*. The process is not linear, nor always identical, not even immediate. Indeed, as we've already highlighted, the health staff is permanently confronted with an *objectivity* problem: although they rely in pretty much consolidated forms of prediction of end-of-life trajectories, the confrontation of these with diverse experiences and expectations brought to end-of-life caring situations by patients and their relatives often obliges them to *compose* their medically-designed trajectories with singular, particular, even unique forms of perceiving and dealing with illness brought to situations of care by different actors. In the process, professionals bind general, consolidated (equipped) forms of medical representation of the ill body with local, particular references to that same body which may transmit to the patients and their families concise but effective anchors for them to understand medically-defined end-of-life trajectories. The body of the patient with its transformations becomes, thus, a support for cognition and a privileged medium used to build local forms in which professionals invest great part of their daily work, forms which are able to function as cognitive clues for the ill persons and their families to interpret end-of-life processes as close as possible to medically-defined end-of-life trajectories. Obviously, these forms in whose definition professionals invest are not as solid, nor do they have the same spatial and temporal validity that their medically-defined dying trajectories have. However, paradoxically, they seem to be suited to propitiate a greater communalization of cognitions among the actors at play in each specific process of dying, something that professionals believe to appease disquietude and discord. We are, thus, in the presence of a mode of communalization which we would call *close communalization by a composition of consolidated and local forms of processing indexical signs of material referents* – which, in these case, are signs descendant from each patient’s body.

This kind of process starts with the admission of the patient and it’s highly dependent on the tact (Breviglieri, 2008b) of professionals to engage and compose those actors’ representations and expectations about the body in its end-of-life with their own medically-designed trajectories, using the signs which come from the patient’s bodies as material anchors (Hutchins, 2005; Martins, forthcoming, b). Although the purpose is to achieve some form of communalization and validity of local cognitive forms around what “really is going on” with the body of the ill person and, expectedly, adjust and coordinate reasoning and expectations about end-of-life as much as possible, they think this can only be made with delicate, case-driven, smooth communication processes.

> “Yes, there are criteria, without a doubt. And even medical criteria, as the matter of fact, that indicates what to expect, isn’t it? That indicates us. However, in terms of expectations [of those involved] it’s different, you know? We have patients who are very ill and who still have a very high expectation [about their future]. Very high. And we see that that person,

> hum, has a very marked asthenia, anorexia, easy fatigue and the person sees this but continues to think that she’s still very well and that this is a fleeting condition.” (Nurse)

> “Often before the apnea, the person starts with some rustling. Therefore, one of the symptoms [by which we perceive the person is entering in the terminal phase] is the person starting with rustling, also there is a certain tiredness, there is a difficulty to expel secretions, so this is one of the first signs, is the rustler. On the other hand, there is a great fatigue, sometimes it’s a look into the void, the gaze, staring at the void, then, hum, and the respiratory part, therefore, comes some dyspnea, some deep breathing with moments of apnea and therefore, these are usually the most important. The body cooling, it’s also important. Hum... So these are, shall we say, the criteria, okay? More clinical ones, which are more visible and which are the most... It’s the anuria too, when the person begins to collapse.” (Nurse)

> “It's one of those things that we have to be very careful about [talking to the family], it's precisely about the prognosis, it’s precisely saying that, ‘- Look, there may be... it may be something that happens suddenly, because a blood vessel can blow’, we have very complex situations here! ‘We can have something sudden, but it can be slow, progressive and calm. But we can always have oscillations.’” (Nurse)

This kind of process is not always one in which each professional approaches patients and their relatives and tries, be it in a delicate manner, to ‘inform’ them about their ‘real’ condition. As the matter of fact, there is a regular and more structured approach conducted by the team in order to discuss a set of themes which are considered to be relevant, also with strong emphasis on the dying trajectories. We are talking about *family meetings*, reunions where the palliative care teams meet the patient’s families, in order to discuss a number of selected themes.

There is much literature[1] about this theme, in which, generally, family meetings, or family conferences, are said to be intending to ensure the quality of care, working in proximity with the families, giving them support and even making them *partners* in caring procedures. Of course, *informing* the families about their relative’s medical condition and the related plan of care is a central aspect of these meetings, as we could observe in our ethnography of hospital wards. Within this information, the focus on dying trajectories becomes a fundamental aspect. Once again, this is a typical moment in which professionals try to ‘inform’ patient’s relatives about the characteristics of medically-designed dying trajectories, with its bodily signs, and of what families should *expect* – both in terms of the process and outcome of the trajectories, both in terms of the plan of care. Even though this plan is to be, at least tentatively, shared and negotiated with the family, the medical aspects associated to the dying trajectories largely structure the frame of negotiation and its limits – although there are cases of discord and professionals don't always get the agreement of the families about their own opinion.

> "In general, the family is looking for us. Trying to talk to us about it, to know where things are, whether it is soon or not, or what they can do or not, what they can talk to [the patient] or not, whether it is beneficial to bring food from home or not. [...] It has already happened, it has already happened in families that are in complete denial – and it is a bit extreme –, we are thinking that death is eminent and the family does not want to accept it and we think it can be very harmful for the patient himself to have his family there... We seek comfort, rest and the family being around the patient saying, '- Get up!', '- Don't you spend so much time in bed!', '- Don't complain so much...' We've already had a case which was most unpleasant... In this case, we had to convene the so-called family conferences where, in a more direct way, we usually try to call the familiar to reality and to what is really happening and, normally, our doctor speaks very convincingly. It's also easier when you have a medicine diploma, which the family or the patient himself understands as relevant." (Nurse)

Information Management

The relevance which palliative care professionals give to ensuring stable forms suited to support common definitions of dying trajectories may be seized if we observe their staff reunions or if we ask them how they manage medical information about dying trajectories as a team. Both the reunions, changes of shift and the everyday activities of the team that require interaction with the patients and their relatives, are carefully monitored having the management of information about dying trajectories in mind. In other words, there is a strict coordination of actions among team members in order not to create any unexpected 'incident' around perceptions and expectations on these trajectories. Besides, the management of medical information about the physical condition of the patients is considered a central aspect of work in palliative care by all the professionals we interviewed.

As the matter of fact, the management of this specific kind of information is something that we could observe is quite frequently an object of great attention in the reunions (generally, weekly reunions) of every palliative care team we attended. Professionals try, in their meetings, to share their insights about 'how much' the patients admitted to the ward and their families know about their 'real' condition, what kind of expectations they are developing over the future trajectories and how they are reacting emotionally if they are aware of the nearness of dying. Of course, this means that, from the very first moment in which a patient is admitted, the team members try, through several delicate modes of engagement in action, to gather information around these points, as we have already highlighted. We could also observe these close gestures between team members, patients and their families, which are widely meant to prepare decision-making processes in staff's reunions.

Changes of shift constitute another kind of situation in which particular care is posed in this type of coordination: most professionals consider this a critical issue to be worked when shifts change, in order not to 'break' the degree of coordination of the team over time.

> "Right from the start, it's very important for us to know what the patient knows, what the family knows, what the patient wants to know, what the family wants us to say and... And this is not (hesitation)... Sometimes... We always make the admission, but we don't always know immediately, it's not all unveiled in the admission and, therefore, we have to understand very well and to draw very well the profile of that family and that patient, you know? Before that we can, let's say, hum, act, say, and in a manner suited not to hurt the sensibility of anyone... and this makes all the difference. It's not easy to do! As we were seeing yesterday, sometimes the first approach is not easy, and yesterday we saw, when we were in our weekly reunion that the Doctor said '-That patient is in denial!'" (Nurse)

> "Everyone has to know how to act for that family, everyone must have the same communication and strategies, everything... because otherwise it's not worth it, if everyone does it their way it's not worth it. And the sharing of information is very important! Very important indeed!" (Nurse)
>
> "If we don't pass on some kind of information [among us], then the language will be different, I will tell the patient one thing, the next one says another, the other comes, says another, and often the patient will explore this, asking you, then asking the other colleague to see if the answer is the same, hum, and if the information is the same, he knows, '-Okay everything is the same, this team works all the same.'" (Nurse)

Conclusion

In this text, we searched to give a pragmatic account of the engagements of professionals of palliative care in order to reduce uncertainty and appease disquietude and discord around situations of end-of-life care. We treated these engagements as investments in the building and maintenance of common forms which are made (the investments) by healthcare professionals. These investments involve defining specific forms which may be suited to achieve the instrumental purpose of reducing uncertainty and appeasing disquietude and discord. We found that the fundamental forms in which professionals invest their work is what can be called end-of-life or dying trajectories. The end-of-life trajectories defined by professionals and communalized among themselves can be called *medically-defined dying trajectories.* These medically-defined trajectories face problems of *objectivity* in palliative care situations involving patients and their families, though. The diversity of views and engagements brought to several identified situations by these actors obviously still puts medically-defined trajectories to test. Analyzing the ways by which health professionals in the observed palliative care wards try to face this kind of problem – or trouble –, we could report that they try to define end-of-life trajectories with the patients and their families which compose their own consolidated forms of defining end-of-life paths with indexical signs referred to the patient's bodies, in a mode of communalizing which we called *close communalization by a composition of consolidated and local forms of processing indexical signs of material referents*. We observed that this mode of communalizing is made only with a delicate sense of *tact* (Breviglieri, 2008b) developed by professionals in their relation with families. Finally, we tried to stress the relevance that the building and the maintenance of the communalized, but singular forms which result from these processes has in the organization of work in palliative care teams. Namely, in what concerns the management of their daily work in the relation with patients and their relatives, be it in the team's reunions, staff's shifts, individual contacts between staff and families and patients or family conferences.

Notes

[1] As mere examples, we can cite the following references: Hudson, Peter, Quinn, Karen, O'Hanlon, Brendan and Aranda, Sanchia. "Family meetings in palliative care: multidisciplinary clinical practice guidelines". *BMC palliative care,* (2008): 7-12; Lautrete, Alexandre, Ciroldi, Magali, Ksibi, Hichem, Azoulay, Élie. "End-of-life family conferences: rooted in the evidence". *Critical care medicine,* (2006/34): s364-s372; Fineberg, Iris Cohen. "Preparing professionals for family conferences in palliative care: evaluation results of an interdisciplinary approach". *Journal of palliative medicine,* (2005/8[4]): 857-866.

CHAPTER TWO

PRIORITY INTERVENTION EDUCATIONAL AREAS AND THE CONSTRUCTION OF THEIR EDUCATIONAL PROJECT: CHALLENGES TO COORDINATION AND ENGAGEMENT AMONG DIFFERENT EDUCATIONAL ACTORS

JOÃO FEIJÃO

Introduction: The Grammar of the Project in the School World

The grammar of the project appears in the management literature and becomes more important from the 80's and 90's of the last century (Boltanski and Chiapello, 2007). It is incorporated into contemporary organizations as an operational requirement. In fact, it is a tool for organizational success, since it allows the organization's strategic planning to be outlined, that is, it allows the direction of the organizational action to be planned (Costa, 2003).

The school, as an organization, was also dominated by the language of the project. This arose in the context of changes in the school world and in the way in which it was regulated. These changes were encouraged by the implementation of neoliberal educational policies, which viewed schools as places with relative autonomy and where the educational project is considered to be the tool which demonstrates capacity (Derouet, 1992).

In Portugal the idea of school autonomy, linked to the school project, appears for the first time in Decree-Law 43/89 of February 3. The document gives no indication, however, of how this project should be achieved and it is not until the publication of Decree-Law 115A/98 of May 4 that even a brief outline is given (Costa, 2003). However, it is necessary to remember that the project should not be conceived solely as one mandated by legislation but also as a project designed by the school actors (Barbieri, 2003). These two dimensions cause some ambiguity in the way the grammar of the project is thought about. On the one hand, it is prescriptive, since it is mandatory in all schools while, on the other, it is perceived as an initiative taken by educational professionals, which aims to diagnose problems within schools and to design and implement strategies to tackle them (Costa, 2003).

In this text we investigate the challenges and the commitments, which the creation of an educational project occasions to the school world and to its educational actors, especially for the adults who work in the school and who participate in the design, implementation and evaluation of this tool. Our investigation aims to look more closely at the tensions, which arise between the various school actors when they are called on to analyse educational problems, to implement measures to assist in remedying them and to evaluate the results of these measures.

We have attempted to approach the question from the perspective of pragmatic sociology, which allows us to understand how people judge the situations in which they are involved, but also how they coordinate to manage tension and resolve critical situations in order to generate a common commitment (Boltanski and Thévenot, 1991; Thévenot, 2006).

This analysis of the challenges for coordination and the actors' commitment to the development of educational project has as its context the schools which participate in the Portuguese Priority Intervention Educational Areas Programme (TEIP). Schools' participation in this programme makes designing an educational project even more complex and unique, in comparison to other non-participating schools, because it requires educational actors to engage with different worlds, governed by different principles, which are often difficult to reconcile (Boltanski and Thévenot, 1991).

It is precisely by setting the TEIP programme and Priority Education Policies in context, in their various stages, that we will begin our examination. Next, we analyze the challenges faced by educational professionals in designing an educational project, based on the perspective of the ministerial team, which coordinates the programme nationally. Finally, we turn our gaze onto the daily work of educational professionals, especially when they meet to discuss their educational project, noting the tensions which arise and the way in which they manage to resolve them and create a common commitment.

The examination and results presented in this text are in the framework of doctoral research[1] still in progress and comprise the preliminary assessments of an exploratory work.

Priority Education Policies, Compensation Programs and Arrangements

The TEIP Programme includes what are termed Priority Education Policies (PEPs). PEPs are defined as “policies, which aim to address educational disadvantage through specific measures or action programmes” (Frandji, 2008: 12). This seemingly simple definition obscures the complexity inherent in trying to provide a single term for these policies. In reality, in different countries they are defined, according to a variety of concepts and no consensus exists around them. Thus, terms such as compensation policies, affirmative action policies and positive discrimination policies can be considered as other ways of defining these policies.

PEPs arose in Europe between 1970 and 1980, in the context of the democratization of education. The policies' main objective was the reduction of educational inequalities and the end of an elitist educational model (Rochex, 2011). However, in historical terms we can trace its origins to the early programmes in the United States in the 1960s with President Lyndon B. Johnson. Compensation policies were designed to combat poverty and support youth from underprivileged social backgrounds, in particularly the Head Start programme, aimed at early childhood. Later the Better Schooling programme for educationally deprived students was also developed, which led to the No Child Left Behind programme (Robert, 2008).

In Europe we can find the origins of these policies in England, especially with the influence of the Plowden Report, produced in 1967. This report acknowledged that there were geographical areas of the country where socially-disadvantaged students were concentrated, and advocated positive discrimination measures, which would require the allocation of financial and human resources to schools in those areas. The latter would participate in a programme, which would be given the name: Educational Priority Areas (Robert, 2008).

This programme was expanded during the Labour government of Tony Blair in the 1990s, which prioritised policies to combat social exclusion and designated Education Action Zones. The programme aimed to improve the levels of educational achievement of the most disadvantaged students.

Although this measure was quite effective in combating school absenteeism, especially at primary level, this was not true for secondary education, as the British government had expected. Consequently, in 2001 the programme was terminated and replaced by the new national Excellence in Cities programme, which provided strategies and resources to clusters of schools to enable them to take action in the areas of teaching-learning, behaviour-assiduity and leadership (Robert 2008).

In France, PEPs were developed in 1981 and gave rise to *Zones d'Éducation Prioritaire* (Priority Education Zones or ZEP), which were designed to combat inequalities in education. The basic idea was that there would be a set of socio-cultural and economic factors, which would explain students' failure and early school leaving. (Robert, 2008). The French government intended not to provide prolonged assistance to these schools and stipulated that support would be available for up to a maximum of four years, so as not to contribute to the creation of school ghettos (Robert, 2008).

The ZEP programme did not develop according to expectations, as the number of participating schools began to increase over time. This forced the programme to be redesigned and relaunched in 1997. At the same time, two new measures were adopted. On the one hand, *Réseaux d'Éducation Prioritaire* (Priority Education Networks or REPs) were created and, on the other, contracts conditional on achievement were agreed between the REPs and the local education authorities. The introduction of REPs allowed priority education policies to operate on a network basis. As a consequence, schools did not become inward-looking and a school ghetto effect was avoided (Robert, 2008).

In Portugal, these priority education policies are the expression of a process of “educational Europeanization” (Sarmento et al., 2000: 107 apud Barbieri, 2003: 45) and may be regarded as a copy of the French ZEP model. However, to understand the origins of educational priority policies in Portugal requires us to go back more than twenty years, to the time after the dictatorship. Portugal was under a dictatorial regime for 40 years, until 1974, which engaged in a struggle against the education sector for ideological reasons. In 1974, the country had the lowest rate of children attending school in Europe, with about 45% of pupils not having completed the six years of compulsory schooling (Correia et al., 2008).

After this period, the education system was reorganized. The Basic Law of the Educational System of 1986, which extended obligatory schooling to 9 years and organized the system of education in cycles, was fundamental to this. There were three cycles: the first cycle (1st to 4th year), the second cycle (5th and 6th year) and the third cycle (7th to 9th year). The last cycle is preparatory for secondary education, where students can follow science or occupational tracks. The law was accompanied by another measure, which is considered to have been the first compensatory programme in Portugal: the Interministerial Programme for the Promotion of Educational Success (PIPSE). The PIPSE, which was created in 1987, was “essentially geared towards the first cycle of basic education and was aimed at reducing underachievement and failure rates in schools" (Correia et al., 2008: 227).

This programme was ended in 1991 and was replaced, in the same year, by a new programme called the Education for All Programme (PEPT), which aimed to "promote equality of opportunity, create the conditions for everyone to access education and to improve school attendance and results" (Correia et al., 2008: 230). It was a programme, which emphasized the importance of looking at the local characteristics of each school and of creating networked partnerships between the school, the wider community and the world of work. The PEPT lasted for six years and was an important contribution to the launch of the Priority Intervention Educational Area (TEIP) programme, which was first established in 1996.

In the same year that the TEIPs were created, the Alternative Studies programme was also implemented. This programme was aimed at young people who were at risk of dropping out of school. The study programme for these young people was more flexible and employed more active pedagogical methodologies. The Alternative Studies programme was updated in 2003 and renamed Alternative Curriculum Paths. Its main objective was "to support young people in the development of their life plan" (Correia et al., 2008: 253).

The Escolhas Programme, created in 2001, was designed to intervene where young people were at risk of exclusion and to assist in the prevention of delinquency or crime. It targeted young people from socially depressed areas of Lisbon, Setubal and Porto. In its second and third phases, in 2004 and 2007 respectively, the programme was extended to other regions of the country (Correia et al., 2008). As we have seen, the aims of these policies, programmes and schemes varied, according to their social and historical context.

This multiplicity of aims was controversial, since these policies were based on concepts, which are complex, namely the notions of equality and justice (Dubet, 2004; Walzer, 1999). The original purpose of these policies was to democratize and to compensate, with the aim of creating a fairer education system. However, equality of access to education did not lead to greater justice because it did not translate into equal opportunities for all (Dubet, 2004). As Michael Walzer (1999) points out, inequalities and injustices arise in all areas and tend to worsen when they are interconnected. The inequalities, which arise in one area, create inequalities and injustices in another. Thus, for example, inequalities within schools have led to new inequalities in employment opportunities.

The same author recognizes that justice is a complex concept. He considers it to be "a human construction and it is doubtful that there is only one way to achieve it" (Walzer, 1999: 23). In addition to the distributive dimension of justice, we also find a dimension already mentioned by Aristotle in his work Nicomachean Ethics: compensatory or corrective justice (Renaut, 2007). Distributive justice implies "the distribution of honours, riches and other advantages by establishing a geometrically proportionate equality in distribution" (Renaut, 2007: 117). Compensatory justice, "establishes an equality, which was destroyed by an unjust act and which was the cause of unfair inequality" (Renaut, 2007: 117).

Priority Education Policies have focused on compensation and therefore on achieving compensatory justice. "But is this concept of justice sufficient if we consider that not all people and groups are equal at school?" (Dubet, 2004: 545). Although school democratization has abolished the principle of indifference to difference, Dubet (2016) is concerned with the growing discourses of individual experiences of discrimination and non-recognition at school. Consequently, the author asks, to what extent does the legitimacy exist to adopt measures aimed at specific groups, when there is still no public recognition of their existence. The notion of equality is still based on the concept of the other as the same as oneself. Consequently, in this debate, it is also questioned, to what extent is it possible to have a form of recognition, which is compatible with the democratic affirmation of equality (Renaut, 2007).

The debate does not end here, nor is it our intention to go further into it. This brief overview is an example of the diversity of often ambivalent views, which lie behind these policies. This presents challenges to educational professionals, who find them difficult to reconcile when required to make decisions about how to act in a fair and proportionate way.

The Three Stages in the Evolution of the TEIP Programme: From Justification to the Challenges for Educational Professionals

The Priority Intervention Educational Areas Programme (TEIP) arose in 1996 in response to the need to rethink ideas of social and educational exclusion, since "the increase in educational qualifications is not necessarily a solution which prevents exclusion" (Barbieri, 2002: 45).

The measure formed part of the territorialisation of educational policies, which can be described as "the transfer of functions from the national and regional level to the local level" (Barroso, 1997: 30 apud Barbieri, 2002: 54). However, in the first stage, the TEIPs were part of a bureaucratic-professional model, with the State playing the leading role in defining norms and rules governing the principle of equal treatment of students (Rochex, 2011). Thus, the programme was characterized more by a process of deterritorialization, since it was “a central administration measure, which originated in the nation-state and less' in the new regional and local identities” (Stoer and Rodrigues, 1999: 9 apud Barbieri, 2002: 57).

Some authors, such as Canário (2004), present a very critical perspective regarding the use of the notion of educational area, arguing that this is confused with the notion of school area. The very term TEIP is not easy to define as the teams responsible for coordinating the program at national level attest:

> “A TEIP is an organizational unit, in an area, which is included in a programme called Priority Intervention Educational Areas. It is an organizational unit like so many others, which exist in the country. Now, it is not easy to define or to describe a TEIP.” (E1)

> “I often have difficulty with this term. I usually say that they are part of the programme. A TEIP is usually a group, which has joined the programme for a reason. The reason is to do with the indicators, which are to do with the school's results.” (E2)

> “An educational area has become a grouping of schools, which needed to find some way of responding to factors causing them to fail to meet quality standards, according to the Ministry of Education.” (E3)

The definition of what an educational territory is does not take in the consensus of those responsible for its coordination on a national level, fluctuating between its characterisation, either as a programme, or as a school group or organic unit with specific features. What does not raise any doubts, is the priority that underlies these educational territories, whereby the “the adjective ‘priority’ thus used, seems to be congruent with an urgency and the marking of the importance of an action plan” (Fradji, 2008: 12): “They are usually, and I can say almost always, inserted in socially and economically disadvantaged places, where this disadvantage is visible, such as in critical neighborhoods or in less stimulating areas” (E2); “They are associated with particularly degraded areas from a social, economic and cultural point of view, where the surrounding environment, given its characteristics of poverty, violence and other social issues, promotes exclusion” (E1).

Some schools, in particular those that are marked by the Ministry of Education as having social and educational problems with an urgent need for an intervention plan, were invited to join the TEIP programme, as one of the interviewees tells us: “The schools were chosen from the results they