Preparing End-of-Life Talks in Palliative Care: Exploratory Remarks on a Social Process

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Abstract
In this article, we develop an exploratory analysis of some of the interactional strategies developed by palliative care (PC) professionals in order to prepare end-of-life (EoL) talks with patients and their families, namely in the frame of specifically social problem-solving work which they develop on a daily basis. In this sense, our object of analysis is not EoL talks in themselves, but the broader social processes that tend to precede them in PC, that is, all the work both of approaching the patient and his or her family and of coordination within the teams that PC professionals routinely do in order to propitiate EoL talk. In this way, we don’t envisage EoL talks as a conversation between two parties, with a patient on one side and a doctor on the other side, but as a wider social process which relies upon strong and previous professional engagement. The analysis conducted herein was carried out on data collected under the projects ETIC – Managing EoL trajectories in palliative care: a study on the work of healthcare professionals (Ref. PTDC/SOC-SOC/30092/2017) and Building paths towards death: an analysis of everyday work in palliative care (Ref. PTDC/CS-SOC/119621/2010), both financed by the Portuguese Science and Technology Foundation (FCT); in particular the data obtained through 17 months (12 in the first project and 5 in the second one, still in progress) of ethnographic observation carried out at two hospital internment units providing PC in Mainland Portugal and 42 (37 in the first project and 5 in the
second one, still in progress) in-depth interviews to professionals in PC – physicians, nurses, and social workers. As main results, we present several theoretical and empirical elements relevant to the analysis of the field of EoL communication in the context of interactions between healthcare professionals, patients and their families. Following earlier studies on the same theme, we show how the work of preparing EoL conversations refers to a broader social process preceding those conversations. We believe that our findings may contribute to elucidating this dimension of the intervention of PC professionals, thus being instrumental for the future definition of systematised guidelines and recommendations in the framework of PC.

**Keywords**
critical moments, end-of-life talks, end-of-life trajectories, palliative care

The sociological study of dying, death, and bereavement is, as Exley (2004) states, a relatively recent field of study and can be dated back to the late 1950s and early 1960s of the XXth century. As Broom and Kirby (2012) argue, despite the fact that more recently we can verify the existence of a growth in sociological work on dying in palliative care (PC) units as a relational experience, little exploration exists about the significance of contemporary family structures and relations in the process. These authors view the relative scarcity of sociological studies which include in their analysis of the experience of dying, not only the experience of the dying persons, but also of their close relatives, as a significant gap in our sociological knowledge and understanding of the dying processes in PC. Meanwhile, other fields of study, such as the health sciences or nursing, have been producing much literature about the theme of families in end-of-life (EoL) care (e.g. Walczak et. al., 2017). Nevertheless, this is a field that, in the words of Broom and Kirby, requires sociological investigation in order to augment the standard focus on individual preferences in PC with sophisticated and nuanced understandings of the family contexts.

Having precisely in mind the need to better understand the relations between patients, their families and healthcare professionals in PC, in our research we address the specific social challenges with which health care professionals are confronted in services of PC. We envisage these challenges in relation to the diversity of modes of experiencing EoL that patients and their families bring to the frame of care. Studies about PC suggest that this type of care tends to be significantly adapted by professionals to each socio-cultural context (Field et al, 1997). As Field et al. argue

> the timing, place, manner and social implications of an individual’s death are shaped by their social position in the society. Age, ethnicity, gender, social class and sexuality all profoundly affect the ways people experiment death, dying and bereavement. [...] Rather than being unaffected by them, differences and diversity in the manner and social implications of dying are both constituted by and constitutive of [...] social identities. (Field et. al., 1997)

Dealing with EoL, death and mourning issues or, in general, in a frame of care, tends to presuppose, thus, some form of professional sensibility to socio-cultural differences.
General, broad solutions seem to be unsuited to cope with something as diverse and socially differentiated as the manner and social implications of death and chronic illness (Martins, 2015). We must note, nevertheless, that the concept of ‘socio-cultural difference’ is broad and unspecific to our purpose. We argue that the analysis of the ways in which professionals deal with dying patients needs more specific concepts, which allow research to go deeper in the enlightening of this issue. That’s why we introduced in our analysis Glaser and Strauss’s concept of ‘career’, both experiential and personal (Glaser and Strauss, 2007), which allows us to connect backgrounds of experience, temporality and actual present situations with which social actors are confronted when dealing with— and defining – EoL or death trajectories.

By proceeding in this way we try to establish an analysis that goes far beyond the themes of medical dominance, whose limitations were already frankly highlighted, for instance by Julia Lawton (2003). Also in the sequence of Lawton’s work about the relevance of lay experiences in EoL, we can say that our article focuses upon, not so much the lay experiences of the disease and of EoL, but mostly the delicate and complex ways in which health professionals in PC deal with lay people and their experience of the disease. In particular, upon a fundamental aspect of this experience which is established along a path of care: the conversation(s) about EoL.

Thus, in this article we develop an exploratory analysis of some of the interactional strategies developed by PC professionals in order to prepare EoL talks with patients and their families, namely in the frame of social problem-solving work which they develop on a daily basis. In this sense, our object of analysis is not EoL talks themselves, but the broader social processes that tend to precede them in PC, that is, all the work both of approaching the patient and his or her family and of coordination within the teams that PC professionals routinely do in order to propitiate EoL talk. In this way, we don’t envisage EoL talks as a conversation between two parties, with a patient on one side and a doctor on the other side, but as a wider social process which relies upon strong and previous professional engagement.

PC is a specific form of health care, dedicated to promote comfort and quality of life for patients in advanced or terminal phase of chronic illness. In our previous research, we analysed the specific social challenges which confront health care professionals in palliative care. We verified that, in these contexts, patients and their families and members of the healthcare teams tend to have different experiential and personal careers in their relation with disease, the organisation of care and EoL trajectories (Glaser and Strauss, 2007, 2009), whose confrontation at the level of interaction produces complex effects in social processes that occur in the daily activity contexts (Martins, 2015, 2018). We observed that professionals tend to believe that this diversity affects the comfort of people at the end of their lives, as it causes uncertainty around the definition and management of EoL and care trajectories (Martins, 2015, 2018).

In this frame, in particular, we addressed the hospital careers of illness that characterise the EoL of many during their aging process (Martins, 2015). These careers exert considerable importance in EoL processes, affecting the interaction around the terminal patient and the organisation of their terminal care (Glaser and Strauss, 2007). The hospital careers of illness include the different experiences that people go through in their relationship with hospitals and healthcare professionals. For instance, some patients
repeatedly return to the same hospital. When this happens, the healthcare teams might react differently to the way they react when a ‘newcomer’ arrives. The extent of the patient’s familiarity with the hospital can also influence their reactions on the path towards death. One aspect of the effect of careers of this type in terminal situations is the conception of time, for example, in the acceptance or non-acceptance of death.

On the other hand, a central aspect of hospital careers of illness in PC is its close relation with the dying trajectories (Glaser and Strauss, 2007) of terminally ill patients. The concept of dying trajectory is quite relevant for our purpose, namely because it is referred to the close relation of observable physiological changes and social actor’s perception and reasoning over them. As the seminal work on dying trajectories developed by Barney Glaser and Anselm Strauss puts it, dying trajectories have shape and duration, but these are not purely ‘objective’ properties: according to the authors, ‘Neither duration or shape are purely objective physiological properties. They are both perceived properties; their dimensions depend on when the perceiver initially defines someone as dying and on his expectations of how that dying will proceed’ (Glaser and Strauss, 2007). Let us say that the use of the concept of dying or illness trajectories until recent times in research about EoL is a fact, namely in relation to different processes of hospitalisation (Harris et al., 2016), its relation with EoL experiences (Lloyd et al, 2016), with communication processes and discussion of life expectancy in EoL care (Walczak et al., 2017) or to address globally the frame of PC (Brant, 2010), only to name a few subjects.

In our work, we address the dying trajectories of patients (Glaser and Strauss, 2007; Martins, 2015, 2018) in close relation to critical moments in the frame of social interactions in PC (Martins, 2015, 2019). We use the concept of critical moment in the sense in which it was defined by Luc Boltanski and Laurent Thévenot, namely highlighting it as a situation where there is discord between relevant actors in view of elements of uncertainty present in situations of co-presence, in our case in situations of palliative internment. The use of the term ‘critical’ derives precisely from the nature of these situations, mobilising the critical competence and skills of social actors (Boltanski and Thévenot, 1999), aimed at reducing the uncertainty inscribed in these very situations and involving discord about dying trajectories (Glaser and Strauss, 2007; Martins, 2015, 2019).

The specific cognitive forms which professionals call information about dying trajectories and which they try to manage for the already exposed purposes are conceptual blends, the use of which is rooted in their daily activity (Hutchins, 2005; Thévenot, 1998). From this standpoint, dying trajectories can be analysed as complex sets of conceptual blends which integrate 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, X-Rays, blood samples, etc.), statistical data about survival rates, etc. These sets of conceptual blends are highly related, in the most relevant cases, to the body of the patient, as a material anchor in which specific medical concepts find root and cognitive support, and for which physiological evolution is the very basis for the definition of dying trajectories by professionals (obviously, dying trajectories are not designated like this by health care professionals).
We already observed that there can exist quite a diversity in the definition of dying trajectories in PC wards, namely because actors bring to the core of these processes different personal and experiential careers (Glaser and Strauss, 2007; Martins, 2015) in their relation to EoL processes. Given the fact that dying trajectories are not exclusively ‘objective’, the perceptions and expectations of social actors, with their specific and differentiated frames of reference developed over time, promote this diversity. But precisely, this is considered to be a problem by the health care professionals in the PC wards that we observed. Not the diversity in itself, but the uncertainty that they believe it can cause, because it is directly related to expectations which, in their view, can create situations of discord and consequent suffering to patients.

Believing that giving insights to the patients and their families about their ‘real’ EoL 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 an attempt to ‘inform’ these actors about medically designed trajectories (Martins, 2018). The process, on the other hand, involves sharing part of the conceptual blends that professionals use in their daily activity with patients and their families, albeit in a lay translation made by professionals ad hoc. The process is not linear, nor always identical, not even immediate. On the contrary, it starts with the admission of the patient, and it is highly dependent on the tact (Breviglieri, 2008) of professionals to engage and try to alter, when they think it’s necessary, the perception of those actors. Although the purpose is to share what ‘is really going on’ with the body of the ill person and, expectedly, adjust and coordinate reasoning and expectations about EoL as much as possible, they think this can only be made with delicate, case-driven, smooth communication processes (Martins, 2018).

In the process, professionals bind general 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 EoL trajectories (Hutchins, 2005; Martins, 2018). The body of the patient with its transformations becomes, thus, a fundamental support for cognition and a privileged medium used to build local forms of perception and communication in which professionals invest great part of their daily work. These forms are able to function as cognitive clues for the ill persons and their families to interpret EoL processes as close as possible to medically defined EoL trajectories.

Promoting comfort in EoL is an obvious purpose of PC, present in specialised literature, which, in accordance with the findings of McNamara, is strongly related to what the author calls professional conceptions of a ‘good enough death’ which is one ‘as close to the circumstances the person would have chosen’ as possible (McNamara, 2004). McNamara’s study about ‘good enough death’ concludes that PC practitioners tend to hope that, through alleviating symptoms and providing support, they may work towards a ‘good enough death’ for their patients. The author states that

[...]therapeutic actions taken by PC practitioners are not only rooted in science, but are overlayed with decidedly moral imperatives to change the circumstances of their patients’ lives, and ultimately, their deaths. The moral imperatives that prompt PC practitioners to act in relation to physical symptom control, do not, however, translate well into other aspects of care. As demonstrated [...], practitioners are far less likely to act with perceived certainty for cases of
psychological, social, and spiritual distress. For these components of the dying person’s experience, the moral imperative may then mean that inaction is more appropriate than action. (McNamara, 2004)

One of the achievements of recent research in this field is the description and analysis in other fields of the daily work of PC practitioners, in which they deal with great amounts of uncertainty, but where they also develop very sophisticated strategies of action in order to promote what they believe to be better overall care. This is the case, namely, of the area of communication and direct social interaction with patients and their families. In this sense, professionals don’t necessarily tend to become ‘inactive’ in these other components of the dying person’s experience, to use McNamara’s expression.

In fact, one of the fields in which research has already given us strong contributions for a more thorough understanding of the contemporary work of PC professionals is the description and analysis of how practitioners communicate about EoL with patients and their relatives. Notably around what is usually called the ‘EoL talk’, which is, along with other situations—such as, for instance, transitions to specialist PC – a critical clinical moment, representing very difficult interpersonal moments for practitioners. Broom et al. (2014). and Pino et al. (2016) also clearly highlight some communication troubles, difficulties and professionals’ interactional strategies over EoL talks. As these authors state, PC professionals can be caught in a tension between the expectation that EoL talk is actively promoted, and the expectation that this is done in a way that is sensitive to patients’ communication needs and preferences. These considerations lead to a core dilemma in EoL communication. If death is a difficult topic, and patients are often reluctant to raise it, then [healthcare professionals] should actively invite such discussion; however, precisely because death is a troublesome topic, invitations to discuss can be inappropriate or very distressing for some patients. (Pino et al., 2016)

According to the findings of these authors, this dilemma of initiating EoL talk is often solved by following up on and encouraging the elaboration of perceived hints that the patients themselves introduce into the conversation with healthcare practitioners, namely physicians. In this way, ‘talk about death could emerge as an elaboration of something that patients have alluded to, with no need to […] unilaterally introducing the topic’. Trying to understand how healthcare professionals observably treat parts of their patients’ talk as relevant to EoL in the course of a consultation, these authors analysed recorded interactions between PC doctors, patients and their companions, examining how doctors engage patients in EoL talk, whether they treat part of the patients’ talk as cues relevant to EoL concerns and whether soliciting the elaboration of cues is a way of ‘navigating the dilemma of EoL talk initiation’. They could, doing so, conclude that by using open solicitation sequences in conversations with patients, ‘doctors provide opportunities to introduce possible EoL considerations and, subsequently, to further elaborate on them’ (Pino et al., 2016).
Methodology

General aspects

The analysis conducted herein was carried out on data collected under the projects ETIC – Managing EoL trajectories in palliative care: a study on the work of healthcare professionals (Ref. PTDC/SOC-SOC/30092/2017) and Building paths towards death: an analysis of everyday work in palliative care (Ref. PTDC/CS-SOC/119621/2010), both financed by the Portuguese Science and Technology Foundation (FCT); in particular the data obtained through 17 months (12 in the first project and 5 in the second one, still in progress) of ethnographic observation carried out at two hospital internment units providing PC in Mainland Portugal and 42 (37 in the first project and 5 in the second one, still in progress) in-depth interviews to professionals in PC – physicians, nurses and social workers. The ethnographic observation records were kept in ‘field logs’, drawn up by five scholarship researchers contracted under the aforesaid projects. The data from the interviews presented here are the result of a categorical analysis of content in which the recording units and context units that refer to discursive segments in which health professionals speak about communication with patients and families around death and EoL have been isolated. After all segments were surveyed, an interpretation of the data was then carried out which revealed what we will call strategies for preparing the EoL conversation. From the isolated segments a selection of significant elements were made to present in the article, which were illustrative of the conceptual interpretation performed.

Research design

In both projects, 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 PC. We chose these professions because (a) professionals of each one of them work directly and in proximity (Martins, 2015) with dying patients and their families; (b) they were, at the time of data collecting, the most common professions in PC teams in our country. Our sample is constituted by the professionals working in PC in the chosen hospitals at the time of the fieldwork process. Fieldwork was accomplished in two hospitals with socially contrastive publics. Hospitals were thus selected according to two criteria: (p) the PC team of each one of them integrated the different professions which were to be observed; (q) they had socially contrastive publics. The publics are contrasting in that the hospitals observed are located in regions with particularly differentiated socio-demographic characteristics in our country, ranging from urban centres with younger and heterogeneous populations to hospitals located in small towns in territories of low population density and markedly rural character, with older populations and less social heterogeneity.

In both studies, all ethical laws and procedures in force in our country were observed and respected. The studies were submitted to the different hospital ethics committees and
also to the regional health administrations of the areas where the same hospitals are located, and received a positive opinion from all of them. All participants gave their free and informed consent for participation in the studies.

**EoL talk preparation**

One of the critical moments that we identified in the organisation of daily professional life in PC is the moment(s) in which professionals try to inform the patient or his or her family about the health condition of the patient at the end of his or her life or, in other words, the tentative discussion of life expectancy in the frame of EoL care. This is often referred to, in the literature, as ‘EoL talk’ (Almack, 2012; Balaban, 2000; Bergenholtz, 2019; Pino et al., 2016).

This puts the problem of how to communicate to patients in PC about their survival expectancy and their predictable EoL trajectory. The moment of communication about this issue is a critical moment because, in addition to its potential susceptibility to the occurrence of situations of discord (for instance, patients or their families in denial), it’s a moment of particular uncertainty for the health team, especially in a sensitive area of their work, since communicating ‘bad news’ or promoting the acceptance of death are considered axial elements of the palliative approach, both in the literature and in the case of the observed and interviewed professionals. This critical moment becomes even more relevant because not only professionals in our observations (n = 42) stated to believe that the patient has the right to know what is his or her real condition and approximate life expectancy, but also this is, according to what they consider to be PC philosophy, a crucial aspect of the process of care (also, more generally, the right to be informed about one’s own health condition is one of the main rights of patients, at least in the light of Portuguese national legislation).

EoL talk is not only a theme which is treated in PC literature (Almack, 2012; Balaban, 2000; Bergenholtz, 2019; Pino et al., 2016), but also a recurring theme in the discourses of the professionals we had the opportunity to observe. As a matter of fact, all of them, without exception, attach great importance to conversations about EoL with patients and families and all of them mention participating, in the specific framework of their profession, in that work. The group (n = 42) of professionals interviewed in the different services which constituted our fields of research also considered that this is an extremely sensitive issue and for which, in their opinion, there are no general models, but rather a need to adjust the communication case by case. How, then, does this type of work take place? Is there any kind of regularity, although in a very open space of possibilities, which can be observed?

In a similar way to what Pino et al. (2016) observe in their study, the PC professionals we observed in our research try to prepare the moment of talking about EoL with patients and/or their families through (a) initial exploratory questions, hints or suggestions or (b) through soliciting an elaboration sequence upon something that a patient and/or his or her relatives say and which is related to EoL. Nevertheless, and differently to the analysis of Pino et al, we found that, although EoL talk is (namely for legal reasons) generally a talk between PC patients/their families and doctors, this medical intervention rests upon a much larger social process which occurs in PC wards and which involves several other
professionals, namely nurses and social workers, in it. As a matter of fact, once again on this point, all the professionals that we interviewed (n=42), when we asked them how they communicate about EoL, talked about some kind of preparation strategy in which they engage in order to help the doctor having an EoL talk (or the doctors themselves try to prepare, with the team, the moments in which to talk). In this sense, although sometimes they do not ‘tell the whole story’ about the disease to the patients at a single moment, they engage in preparation strategies which involve initial questions or asking elaboration sequences.

**EoL talk as a wider social process: preparation strategies**

The use of clues, or tips, is a form of approach that professionals use to encourage conversation about EoL. In fact, several of them, from two different PC teams, even use a particular, and identical, expression to address the way they try to do this: the idea of giving ‘warning shots’. Warning shots are, as stated by these professionals, small clues that are being introduced in the interactive and conversational processes of between professionals and patients/families, which aim to assess the readiness of patients to talk about EoL or, even, to trigger this same conversation, mainly if a doctor is present. The use of this interactional strategy reveals what Marc Breviglieri (2008) calls the ‘tact’ of professionals, a specific set of skills through which they seek to compose medical knowledge about EoL trajectories with the interactional specificities of a situation of a direct, non-mediated relationship with a patient and/or his or her family.

I2P – It’s not easy, because we don’t know for sure what the patient or even the family wants to know, because there may even be a day when the patient feels better, more strong and even wants to talk about it. But possibly, in the afternoon or the next day, he already feels down again and doesn’t even want to hear about it. So, really, we try to give some warning shots, and we also try to see what the person wants to know and learn to know and shape, because we have to adapt, really, to the person’s personality and see how far we can go and that’s enough, just watch and be on the lookout for small signs, because, I think it’s difficult, but people manage to convey this to us, whether or not they want to know more.

Another strategy often used, and in an associated manner, is asking patients to elaborate upon some subject (Pino et al., 2016), in order to seek, through indirect questions, to know the degree of knowledge that the patient and his family have about the disease, the expectations developed which are based on that degree of knowledge and the type of reaction that they are having. This is a strategy used by professionals in the different teams participating in our research and which, according to them, is not, as a rule, done at once, but at different moments and in a diversity of interactional situations within PC, once again using a complex sense of tact and in the framework of the building of a relationship of trust between professionals and patients/families:

I3N–This has to be made step by step, right? We will ask more or less what does he know, right? . . . about the disease. [. . .] In what concerns the disease, we always try to know what he already knows, what some doctor has already told him, if he can improve, if he cannot improve, but at the same time, we are not going to give too much information. Because then, well . . . there
are patients who get here and have no idea of the severity of the disease and then there are family members, too, who do not want this information to be transmitted. But, it’s always like this, it’s on this basis of a step by step approach, we will talk to him to try to know what he knows and also giving some . . . Some little information.

I4SW—In a first phase we try to understand where the perception of the patient’s family is in relation to the prognosis, we already had all kinds of cases, patients who are not informed about their condition at all, or cases in which only the family has some information and the patient doesn’t, or the other way around. The first thing to do is to identify at what stage is their perception and according to it, or to the patient’s intention, which is always the one that we try to safeguard above all, or if the patients is unconscious or allows it, we try to intervene also with the family, but yes, we directly or indirectly always end up making a preparation [of EoL talk].

**EoL talk as a wider social process: coordination of actions and more structured approaches**

This kind of process is not always one in which each professional approaches patients and their relatives and tries to prepare an EoL talk. There is a more structured approach conducted by the teams in order to discuss a set of themes which are considered to be relevant, also with strong emphasis on the dying trajectories, and which are also suited to prepare EoL talks with the patients (since it is directed to the families, mostly). We are talking about family meetings, reunions where the PC teams meet the patient’s families, in order to discuss a number of selected themes.

Family meetings, or family conferences, are usually envisaged in the literature (e.g. Fineberg, 2005; Lautrette et al., 2006) of PC as intending to ensure the quality of care, working in proximity with the families, giving them support and even making them a partner in caring procedures. Of course, informing the families about their relative’s medical condition and the related plan of care is a fundamental aspect of these meetings, as we could observe in our ethnography of hospital wards. Within this information, the focus on communicating about dying trajectories and life expectancy becomes a central aspect. This is a typical moment in which professionals try to ‘inform’ patient’s relatives about the characteristics of medically designed dying trajectories 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 that there are cases of discord and professionals don’t always get the agreement of the families about their opinion.

I2N: In general, the family is looking for us. Trying to talk to us about it, to know where things stand, whether it [death] will be 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, there are families that are in complete denial—and it is a bit extreme -, we are thinking that death is imminent and the family doesn’t want to accept it and we think it can be very harmful for the patient himself to have his family in such a state . . . 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 relatives to reality and to what is really happening and, normally, our doctor speaks very convincingly.

The need of coordination for the detailed management of information and the way it is revealed to patients and their families is something that is particularly sharp in everyday work in PC. Another daily moment in which this is particularly relevant is in shift changes. Here, it’s not just a matter of passing medical information from professionals from one shift to the next, but also a set of clues, considerations, more ‘informal’ aspects that are, however, critical in the management of information about EoL trajectories. This gives us one more clear indication of the prevalence, in PC, of a careful preparation of EoL talks by healthcare professionals or, as we’ve already stated, as a broader social process:

I11N: We have the shift change and we end up sharing things that we think are more important. Conversations that seem to us to be more important to the person, or that demonstrate some kind of . . . that the person is not very suited to the situation. Therefore, whenever we think it can happen, to the person, or to the family. We share, we end up sharing, and then, too, we do not run the risk of someone giving information and coming next and giving slightly different information, which people may perceive differently. Of course, there are things, there are techniques that we learn to deal with certain questions, such as ‘How long I will live’, etc.

The following passage is paradigmatic of the relationship between patients’ attempts to know their condition (when it happens) and the subtle work of information gathering by professionals (and, in this case, also volunteers), but also of the relevance of formal coordination, in the background, between professionals, in order to communicate with patients:

I16N: We have patients who ask a lot of questions [. . .], they try to find out everywhere, sometimes they even ask questions to volunteers, and volunteers tell us [. . .] We have all seen such situations. Whenever the patient asks some kind of question, we talk to everyone [in the team]. It’s not that we can get everyone together, but there are important messages to pass on to the colleague at the shift change meeting, for instance. When it happens to the medical assistants, people ask a lot of questions and as a general rule the assistants tell us or say what they should say, ‘Look, I’ll talk to the nurse and I’ll tell you, or the nurse will talk to you’. Family members also ask volunteers some questions to try to find out more information. This is the strategy we have. There is an open relation between us and they say ‘-Look, the patient asked me this’. . . and we talk among us, we pass the message so that there is a common message and the reading is common. We have a weekly multidisciplinary meeting and a summary of the whole week, and a decision discussed by everyone as to which path is the best [to talk with patients and their families]. Not only for the nurses, but also for doctors, psychologists, social workers . . .

Discussion

In this article, we highlighted some of the specific ways in which PC professionals prepare themselves, patients and their families to engage in EoL conversations. Like Pino
et al. (2016), we found that hints and clues, or asking for the elaboration of sequences, are fundamental aspects of interaction around EoL talks. Differently from these researchers’ work, however, our analysis included other health professionals, namely nurses and social workers, which allowed us to see how EoL talks, more than just being a private moment of conversation between a doctor and a patient or his family, are usually only a moment, although a very critical moment, of a broader social process in which the PC team gets involved, from the identification of any clues that may indicate a need or willingness of the patient to have this conversation to well-structured modalities of communication within the team, in order to obtain good information management. Another relevant difference compared to the work of Pino et al. is the analytical articulation of these processes with the management of EoL trajectories. Thus, this social process, in addition to going beyond the authorised spokespersons for communicating about prognosis—the doctors, is also just a particular aspect of broader processes for managing information on life expectancy carried out by the team as a whole and over time, as we’ve seen elsewhere (Martins, 2015).

Our study has both strengths and limitations. One strength is our research design, combining ethnographic observation with interviews, which allowed us to gain a more global perspective of day-to-day work in PC and thus the diversity of situations in which professionals converge to prepare communication with patients and their families around their life expectancy. The conceptualisation we have been developing around the temporality of EoL processes and the difficulties of composing different experiences of actors in co-presence in PC finds, it seems to us, a strong conceptual anchor in the concept of trajectory. It’s because we envisage trajectories as something which occurs in time that we also see professional work as a follow-up to these trajectories and we break, so to speak, with more fixist perspectives of EoL analysis. In addition, and more fundamentally, we believe we have been able to bring additional elements to the analysis of a dimension of the work of health professionals in PC of great relevance, the field of end-of-life communication in the context of interactions between professionals, patients and families. Following earlier work on the same theme, we have been able to note how the work of preparing EoL conversations refers to a broader social process preceding those conversations. The opening of the ‘black box’ of communication and social interactions in these contexts represents, in our view, an advance on previous observations, particularly at the time of McNamara’s work (McNamara, 2004), which identified areas such as dimensions of daily work often undervalued in practice by professionals. We have also managed to do this by linking these issues to the more general aspects of EoL trajectories and hospital careers of illness. The main limitation is that we could only make an exploratory analysis, namely because one of the projects on which our data is based is still in progress.

Future studies should try to articulate the analysis of the preparatory moments of EoL talks with the development of the talks themselves, as well as the sequence of events after these talks; after the moment in which the patient is defined as terminal and accepts (or not) this definition, which transformations occur in the interactions between different actors in PC? And what other critical moments occur in the case of, for example, ‘successful’ EoL conversations, and how do they differ from critical moments that may occur as a result of not so successful EoL conversations, at least from the professionals’ point
of view? Furthermore, we believe that this sociological work of elucidating this fundamental dimension of the intervention of PC professionals can be instrumental in defining future systematised guidelines and recommendations for the construction of a more structured approach, although necessarily adapted to each context, in the framework of PC. This can be an important contribution of Sociology and Social Sciences to the models of intervention and professional practices in this field. These are just some of the questions we would like to come back to in the future.

Funding
The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Oriana Brás has conducted ethnographic fieldwork and interviews with health professionals and data analysis in the framework of the project reference PTDC/SOC/SOC/30092/2017.

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Note
1. We use the initials ‘P’ for interviews (letter ‘I’) with physicians, ‘N’ for nurses and ‘SW’ for social workers.

References
Almack K, Cox K, Moghaddam N, et al. (2012) After you: Conversations between patients and healthcare professionals in planning for EoL care. *BMC Palliative Care* 11: 15.
Balaban RB (2000) A physician’s guide to talking about end of life care. *Journal of General Internal Medicine* 15(3): 195–200.
Bergenholtz H, Timm HU, Missel M, et al. (2019) Talking about end of life in general palliative care – what’s going on? A qualitative study on end of life conversations in an acute care hospital in Denmark. *BMC Palliative Care* 18: 62.
Boltanski L and Thévenot L (1999) The sociology of critical capacity. *European Journal of Social Theory* 2(3): 359–377.
Brant JM (2010) Palliative care for adults across the cancer trajectory: From diagnosis to EoL. *Seminars in Oncology Nursing* 26(4): 222–230.
Breviglieri M (2008) L’individu, le proche et l’institution. Travail social et politique de l’autonomie. *Informations Sociales* 145: 92–101.
Broom A and Kirby E (2012) The EoL and the family: Hospice patient’s views on dying as relational. *Sociology of Health and Illness* 35(4): 499–513.
Broom A, Kirby E, Good P, et al. (2014) The troubles of telling: Managing communication about the end of life. *Qualitative Health Research* 24(2): 151–162.
Exley C (2004) Review article: The sociology of dying, death and bereavement. *Sociology of Health and Illness* 26(1): 110–122.
Field D, Hockey J and Small N (eds) (1997) *Death Gender and Ethnicity*. London: Routledge.
Fineberg I (2005) Preparing professionals for family conferences in PC: Evaluation results of NA interdisciplinary approach. *Journal of Palliative Medicine* 8(4): 857–866.
Glaser B and Strauss A (2007) *Time for Dying*. New Brunswick, NJ: Aldine Transaction.
Glaser B and Strauss A (2009) *Awareness of Dying*. New Brunswick, NJ: Aldine Transaction.
Harris ML, Dolja-Gore X, Kendig H, et al. (2016) EoL hospitalisations differ for older Australian women according to death trajectory: A longitudinal data linkage study. *BMC Health Services Research* 16: 484.

Hutchins E (2005) Material anchors for conceptual blends. *Journal of Pragmatics* 37: 1555–1577.

Lautrette A, Ciroldi M, Ksibi H, et al. (2006) EoL family conferences: Rooted in the evidence. Critical Care Medicine 34: S364–S372.

Lawton J (2003) Lay experiences of health and illness: Past research and future agendas. *Sociology of Health and Illness* 25: 23–40.

Lloyd A, Kendall M, Starr JM, et al. (2016) Physical, social, psychological and existential trajectories of loss and adaptation towards the EoL for older people living with frailty: A serial interview study. *BMC Geriatrics* 16: 176.

McNamara B (2004) Good enough death: Autonomy and choice in Australian palliative care. *Social Science & Medicine* 58: 929–938.

Martins A (2015) Building paths towards death: Sociological portraits of discord in family relations of the elderly in palliative care. In: Resende J (ed.) *The Making of the Common in Social Relations*. Newcastle Upon Tyne: Cambridge Scholars Publishing, pp. 6–21.

Martins A (2018) The delicate composition of commonality in palliative care: Between critical moments and invested forms. In: Resende J, Martins AC, Breviglieri M, et al (eds) *Challenges of Communication in a Context of Crisis*. Newcastle Upon Tyne: Cambridge Scholars Publishing, pp. 7–17.

Martins A (2019) Managing end-of-life information in palliative care: Between discord and conceptual blends. In: Albuquerque C (ed) *Emerging trends and innovations in privacy and health information management*. Pennsylvania, PA: IGI Global, pp. 169–187. Available at: https://www.igi-global.com/book/emerging-trends-innovations-privacy-health/218138

Pino M, Parry R, Land V, et al. (2016) Engaging terminally-Ill patients in EoL talk: How experienced medicine doctors navigate the dilemma of promoting discussions about dying. *PLoS ONE* 11(5): e0156174.

Thévenot L (1998) Pragmatiques de la connaissance. In: Borzeix A, Bouvier A and Pharo P (eds) *Sociologie Et Connaissance. Nouvelles Approches Cognitives*. Paris: Éditions du CNRS, pp. 101–139.

Walczak A, Butow PN, Tattersall MHN, et al. (2017) Encouraging early discussion of life expectancy and end of life care: A randomised controlled trial of a nurse-led communication support program for patients and caregivers. *International Journal of Nursing Studies* 67(2017): 31–40.

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Date submitted 4 May 2020
Date accepted 1 February 2021