Chapter 7
Managing End-of-Life Information in Palliative Care: Between Discord and Conceptual Blends

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ABSTRACT

In this chapter, the author develop a sociological analysis of the role played by professional management of information about patients’ end-of-life (EoL) processes in palliative care (PC). Thus the author will thus highlight the processes by which PC professionals manage private health information about patients in the frame of this type of care. Thus the author will show how managing information about prospective EoL trajectories by healthcare professionals is one of the major challenges in their daily work in PC wards. The author verifies 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 organization of care, and EoL trajectories, whose confrontation at the level of interaction produces complex effects in social processes that occur in daily activity contexts of PC.

INTRODUCTION

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 50’s and early 60’s 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 units as a relational experience, little exploration exists about

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the significance of contemporary family structures and relations in the process. These authors view the relative scarcity of sociological studies that include in their analysis the experience of dying - not only the experience of the dying person, but also of their close relatives -, as a significant gap in the sociological knowledge and understanding of the dying processes in palliative care. This is thus a field that, in the words of Broom and Kirby (2012), requires sociological investigation, in order to augment the standard focus on individual preferences in palliative care with sophisticated and nuanced understandings of the family contexts. Having precisely in mind the need to better understand the relationships between patients, their families and healthcare professionals in palliative care, in our research we addressed the specific social challenges to which health care professionals are confronted with in services of palliative care. We envisaged these challenges in its relation to the diversity of modes of experiencing end-of-life that patients and their families bring to the frame of healthcare. One of the main purposes of the research was, thus, to describe and analyse the ways by which healthcare professionals deal, in palliative care, with complexity in social situations, namely complexity caused by the confrontation, at the level of interaction, between different experiential and personal “careers” related to end-of-life care.

**BACKGROUND: THE BODY AS A MATERIAL ANCHOR FOR COGNITIVE PROCESSES**

In this Chapter, the author develops an exploratory analysis of the role played by distributed cognitive processes in palliative care, namely in the frame of specifically social problem-solving work developed by palliative care professionals. Palliative care is a specific form of healthcare, dedicated to promote comfort and quality of life for patients in advanced or terminal phase of chronic illness. In this type of care, the intervention of professionals needs to address frames of action which typically involve the private sphere of patients and their families. In these frames, one of the major elements which compose a significant part of the private sphere of patients is their body, namely the parts of it usually covered and protected from public scrutiny. Unveiling a part of what happens in this kind of frame is the purpose of this text.

In our analysis, we use the concept of *material anchor*, built by distributed cognition scientist Edwin Hutchins (2005), which allows to analyze and give centrality to the body of the patient as a particular material structure. Social actors in palliative care use this material anchors in the coordination of their actions, namely by coordinating internal (cognitive) structures with external (the body of the patient) structures. Material anchors play a relevant role in reasoning – or, in other words, in cognitive processes -, namely when social actors are in a situation which
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