



The Left Atrium

Narrative endings

A few months to live: different paths to life's end

Jana Staton, Roger Shuy and Ira Byock
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Drawing on the experiences and perspectives of nine terminally ill people and their families, *A Few Months to Live* provides a powerful and moving account of the diverse ways in which people approach the last months and days of their lives, and of the difficulties and challenges faced by caregivers and loved ones.

The book is based on a study conducted by two of the authors in 1997 as part of the Missoula Demonstration Project, which was created to study end-of-life experiences and to initiate improvements in end-of-life care in Missoula County, Montana. The aim of the authors — Jana Staton and Ira Byock worked on the Project, and Roger Shuy is a research professor of linguistics — is to provide a record of the lived experience of dying and of caregiving.

The narrative accounts of patients, caregivers, family members, friends and others were derived by combining tape-recorded conversations, observations, field notes and printed materials. The researchers conducted informal tape-recorded conversations with each patient until the time of death and conducted interviews with caregivers from between two and ten months after the patient's death.

A Few Months to Live is intended for a broad professional audience, including not only clinicians and health care researchers, but also their colleagues in a wide range of disciplines, including sociology, philosophy, theology and public policy. Addressing such a diverse audience is challenging, but the authors succeed by covering a wide range of topics. The book's 12 chapters address issues related to health professional-patient communication, the process of

treatment planning and the way in which patients' choices are made, knowledge of illness, attitudes toward pain and death, family caregiving, personal growth, spiritual concerns and the search for meaning, and the many complexities surrounding grief and bereavement. One of the main strengths of the book is that it captures the less visible elements of patient and family perspectives. Participants describe what it is like to cope with unrelenting pain, increasing physical incapacity, financial strain related to rising medical expenses, and changes in relationships.

The voices of patients are poignant and compelling as they describe their ways of finding meaning, hope and a sense of personal control and dignity in spite of their illness.

The first chapter of the book introduces the nine study participants and their families, all of whom were residents of Missoula County in 1997. This chapter provides a profile of each patient, detailing his or her diagnosis, treatment and level of functioning at the time of the study, as well as information on the family constellation and the nature of the family's involvement in care.

Throughout the book, the reader is witness to specific aspects of the patient's and family's experience of terminal illness, such as the process of planning care, the patient's knowledge and understanding of the illness and the multifaceted challenges of daily coping. Through narrative, the authors

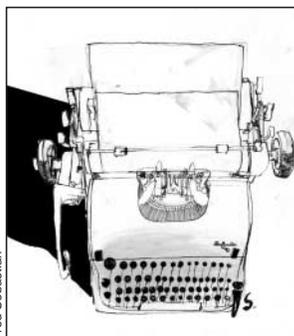
convey the various ways by which patients and their family members attempt to reconnect, to nourish the self and to find meaning despite physical and emotional trauma.

Although each chapter invites consideration of some theoretical aspect of end-of-life care, it is the personal experiences of patients and their family members that lead the reader to ask critical questions and re-examine the assumptions of palliative care. Three chapters, for example, deal with communication in relation to knowledge of illness, and with theories of knowledge in a "closed context" and in an "open context." It is, however, the frank and honest replication of the patient's "voice" that helps us to understand what the patient prefers to "know" and to understand in the context of his or her illness and prognosis.

In the course of reading this book, it becomes evident that the nine people in the study are both living their stories and transforming them into words. Many of the accounts, especially those in a chapter on final days, are necessarily presented from the perspective of close family members or caregivers rather

than of the patient. Some readers may object that these accounts are shaped more by the narrator than by the patient. Undoubtedly, we need to be aware of the relationship between the patient and the narrator. The researchers do attend to the problem of losing the patient's voice, however, by presenting the narrative accounts of the closest caregiver.

That being said, what may be most important to observe in these constructed accounts is what we learn about the caregiver-narrators. From them we learn about the importance of human connectedness and close family



presence in the patient's final days, and that personal relationships remain a primary source of care for people who are terminally ill. The narratives of family members, close friends and informal caregivers reflect strength, wisdom, empathy and active listening, as well as loving support and care. This is a welcome balance against our tendency to professionalize human problems.

In their introduction, the authors ask, "What individual and collective responsibility do we have toward people who are dying, family members, friends, neighbours? What value is there in the last phase of life? Can there be any value in the process of dying?" In striving to provide narrative accounts that extend "beyond the usual categories of facts and figures of death and

dying," *A Few Months to Live* offers a moving, provocative and frank response to these questions.

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Lifeworks

"If the soul is nourished ..."

As a child of a Cold War warrior and an adult media junkie I arrived in Moscow with a burden of preconceptions. I anticipated a grey city where most residents lived in poverty, beset by Wild West-style crime and great uncertainty. Unfortunately for Muscovites, I found this was more or less true, but I also discovered something quite extraordinary: the residents' passion for the arts, education and culture. From candy-bar wrappers adorned with replicas of Russian classics, to metro stations that look like palaces, to statues of literary greats seemingly dominating every corner, residents enjoy a daily dose of a rich cultural heritage.

This cultural richness stems, at least in part, from Lenin's law to cherish, pre-

serve and restore the country's heritage (except churches of course, the most magnificent of which, Christ the Redeemer, was literally blown apart). Communist Russia celebrated the existing culture that fit its ideals and fostered its own brand of art. Artists, at least those with the right politics, were revered and were given the choicest apartments and other perks. Of course, art often served the "greater purpose" by glorifying Communist ideals. Thus, peasants, factory workers and heroes of the Revolution were commonly depicted in works of art. Not that state- or church-sponsored art is anything new; indeed, for 600 years (until the 17th century) Russian art was predominately ecclesiastical. And, one could argue, in times

of widespread poverty this sort of sponsorship is the only thing that allows art to exist. But in Communist Russia, art was also created for sheer aesthetic pleasure. The Diamond Fund, a repository of the former Soviet Union's biggest and most remarkable gems, for example, contains a three-metre long section of Soviet-era jewellery that includes an exquisitely wrought fireworks-shaped brooch. These pieces have never been worn; they were created to perpetuate the jeweller's craft for the enjoyment of all.



Detail from a depiction of Stalin's Gulag in Moscow's Graveyard of the Fallen Monuments. This "graveyard" contains some of the sculptures removed from around Moscow at the end of the Soviet era — mostly because they were being vandalized — and provides an outdoor atelier for present-day sculptors. Ironically, this work is placed behind a giant, slightly damaged statue of Stalin.



Pushkin gazes at a Martini advertisement in Tverskaya Square

This cultural legacy of Communism endures. A decade after the USSR was dissolved, this sprawling low-rise city of 10 million still features more than 40 museums and galleries, documenting history, art, the metro, architecture, literary heroes and even vandalism. Moscow also has seven large classical music concert halls, plus the world-famous Bolshoi Theatre, and more than 50 big theatrical companies, including the 60-year-old Gypsy Theatre.

The Muscovites I got to know are extremely proud of this cultural richness. "When we were growing up [in the 1960s and 70s], we were told that your personal success wasn't important, your personal development was," says