

## *End-of-Life Care in Turkey*

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Most physicians confront the moral and technical challenges of treating persons who are coming to the natural end of their lives. At the level of the health system, this issue becomes a more pressing area for reform as premature death decreases and more people live a full life span. Well-developed countries and international organizations such as the World Health Organization (WHO) and the Organisation of Economic Cooperation and Development (OECD) have made recommendations for improving healthcare problems in aging societies.<sup>1-3</sup> Turkey belongs to the WHO and the OECD. This article describes end-of-life healthcare in Turkey, the design of the healthcare system to meet this need, challenges that should be addressed, and solutions that would be appropriate to Turkish culture and resources.

### **The People and Healthcare System of Turkey**

Turkey provides primary, secondary, and tertiary healthcare. The healthcare system in Turkey is based in local primary, outpatient healthcare centers. About 5,785 of these have physicians, and midwives run about 11,738 smaller rural units.<sup>4</sup> The Ministry of Labor and Social Security has established an additional system of local clinics for workers. Collectively, this primary healthcare system focuses on preventing infectious disease and on treating acute and chronic disease. Secondary healthcare is structured around state hospitals, with a national insurance system for workers and their dependents managing its own state hospitals. University hospitals are the tertiary healthcare facilities.

The healthcare system has evolved since the founding of the Turkish Republic in 1923 and the socialization of healthcare in 1961. During the early years of the Republic, the highest priority was fighting infectious diseases, especially malaria, tuberculosis, trachoma, smallpox, and leprosy. Government efforts to reduce these diseases were very successful.<sup>5</sup> With time, however, attention waned and malaria and tuberculosis increased in prevalence to again become a focus of concern.<sup>6</sup> In 1961, Turkey socialized its healthcare system to focus on preventing disease, promoting health, and providing treatment and rehabilitation.<sup>7</sup> This legislation was intended to make multidisciplinary health services available and accessible in every part of the country. This policy defined health as physical, psychological, and social well-being, which is very similar to the WHO's *Declaration of Alma-Ata* that was adopted 17 years later.<sup>8</sup>

There were many difficulties in implementing this reform. More emphasis was put on treating disease rather than on preventing illness. Patients and

families were frustrated by inefficient referrals to specialists by the primary care system and elected to directly seek specialists, thereby overloading the limited capacity for specialized care. The large state hospitals and hospitals for workers handled 71% of total outpatient visits.<sup>9,10</sup> These hospitals are often crowded and have long waiting lists. Despite the overburdened secondary and specialized system, the local primary care facilities continued to play a key, if somewhat autonomous, role especially in immunization and mother-child care. Table 1 gives a demographic overview of Turkey.

Population migration from rural areas to urban settlements has also challenged the health system. Urban migration began in the mid 1950s and continues to accelerate. In 1923, at the founding of the Republic, 75% of the population lived in rural settlements; today 60% live in urban areas.<sup>11</sup> Large shantytowns largely housing unemployed or underemployed people surround major cities. The residents of these settlements stay until they find a job that enables them to live in the city. Health conditions in the settlements are poor and are perceived as a threat to the cities they envelope.

### End-of-Life Healthcare in Turkey: Challenges and Areas for Reform

For centuries, Turkish people died at home under the care of family and where religious rituals were performed at the last moments of life. In rural settlements, death still takes place in the home in the presence of relatives. Urban migration has been one of the forces that has moved nearly 60% of deaths to hospitals.<sup>12</sup> Another reason for the change in the location of death is the need of women relatives, who used to provide home care to dying persons, to work. Many patients spend their last days traveling to distant hospitals or getting through the long waiting lists.

**Table 1.** Demographics of Healthcare System, and People (Age and Causes of Death)

Crude death rate (1998 <sup>a</sup> ):	.60%
Life expectancy at birth (1998 <sup>b</sup> ):	69
Population over 60 <sup>c</sup> :	8.4%
Cause-specific mortality rates for people 65 years old and older (1997) <sup>d</sup>	
Heart diseases (except ischemic heart diseases)	43.3%
Malignant neoplasms (including neoplasms of lymphatic and hematopoetic tissue)	10.8%
Cerebrovascular diseases	8.4%
Ischemic heart diseases	4.5%
Diabetes Mellitus	1.7%
Hypertensive disease	.5%
All the other diseases	12.8%
Symptoms and ill-defined conditions	12.7%
All the other causes	4.3

<sup>a</sup>Turk Tabipleri Birliđi. *Turk Tabipleri Birliđi (TTB) Sađlık İstatistikleri 2000* [Turkish Medical Association (TMA) Health Statistics 2000]. Ankara: Turkish Medical Association; 2000. (In Turkish.)

<sup>b</sup>See note a, TTB 2000.

<sup>c</sup>World Health Organization. *World Health Report 2001* [2000 statistics]. Geneva: World Health Organization; 2001.

<sup>d</sup>Devlet İstatistik Enstitüsü [State Institute of Statistics]. *Turkiye İstatistik Yilligi* [Annual Statistics of Turkey] *Mortality Statistics from Provincial and District Centers*. Ankara: State Institute of Statistics; 1997. (In Turkish.)

Relatives often take care of persons who are old, disabled, or terminally ill. There are no hospices in Turkey. Home care services are very limited—most are run by private health centers and are expensive. Private home care services are not covered by state insurance, which is the main insurance system in Turkey. There is inadequate support for relatives who care for dying patients at home. Home care requires a healthcare system to make it work as a humane and efficient form of care, so that it is not a form of neglect. Family caregivers face many problems. There is a lack of visiting nurses to support patients and instruct caregivers. Lacking proper assistance, pain control, and dietary advice, patients are prone to develop bedsores and infections at an earlier stage. These events can cause suffering and early death, and they increase the chance that the patient returns for a hospital admission that would have been avoidable if the patient had been properly cared for. Inefficient home care increases the heavy burdens on families, impoverishes them, and takes them out of the workforce.

Narcotics are often not available to meet the needs of dying patients with chronic pain. Many private pharmacies shun the bureaucracy and the potential liability that goes with dispensing “green” prescriptions (for addictive or abusable drugs) and “red” prescriptions (for narcotics). The difficulty in finding a healthcare professional to come to the home to dispense, administer, monitor, or instruct in the proper use of opiates encumbers or entirely obstructs home care with narcotics. Undertreated pain and the lack of a means to secure access to opiates lead people to seek overloaded hospital-based clinics or avoidable and costly inpatient treatment.

Hospitals and their staff are not organized or trained to provide palliative care. Two authors (NB, MC) asked administrators of seven university hospitals and nine large state hospitals in Turkey’s three major cities of Ankara, Istanbul, and Izmir if they had policies for end-of-life care, pain management, or DNR orders. No hospital had a policy on any of the three subjects.

Dying inpatients are often placed in what healthcare professionals informally call “agonal rooms.” These are often in less noticed areas of the hospitals. Patients receive relatively little attention, and the specific medical needs of persons at the end of life go unmet. Needlessly hospitalized debilitated patients are more likely to acquire and carry drug-resistant infections that are costly to treat and that endanger other inpatients. This problem is compounded when such patients are then isolated, which deprives them and their families of important interpersonal relationships at the end of life. Hospital staff do not teach relatives how to better manage the pain and disabilities of frail persons if the patient is discharged. Clinicians do not use these inpatients as opportunities to teach the care of dying patients to the next generation of professionals. Some patients are subjected to useless resuscitation procedures for educational purposes. The dying person is often alone in an institution from which he or she or relatives sought help.

A disabled person without relatives to provide home care may be admitted to the relatively few and widely dispersed nursing homes. There are public nursing homes for poor people and private nursing homes for very rich people. Nursing homes often do not accept terminally ill patients needing continuous medical care. When a resident needs medical care, the facility either calls for an attending physician or the patient’s private physician or asks the patient’s family to take care of the situation.

There is a lack of a professional standard for truthfully telling patients and their families about the severity of their situation. Until patients understand their condition, they will request costly and ineffective medical treatment. Civaner and Terzi found that 7% of patients signing a standard hospital consent-to-treatment form did not know their diagnosis. Furthermore, 53% of patients who gave written consent to hospital procedures said that they were not adequately informed, with more than one-third saying that they did not understand what they were told.<sup>13</sup> Consent is incomplete if a patient does not understand the method of treatment, side effects, chances of benefits, or the possible benefits of alternatives to a recommended treatment. For example, a patient may consent to ineffective chemotherapy for cancer without being aware that pain control alone may be cheaper and give them a better quality of life. There is no legal framework for advance directives. The lack of forthright discussions of terminal illness means that some patients are admitted to intensive care units—an improper use of scarce and costly resources that may harm other people's ability to get aggressive life-saving treatment.

### **A Treatment Philosophy for Dying Patients**

The lack of a system for good end-of-life healthcare is causing increasingly serious problems for Turkey as its population ages and as more advanced, and costly, medical technology is introduced. Turkey can have a better and more efficient healthcare system if it builds a better healthcare system for people who are nearing the end of their lives. To do so, it must begin by articulating a treatment philosophy for the care of dying patients. This treatment philosophy should describe the kind of care, the level of services, and the quality of services that incurably ill persons can expect. This program must acknowledge and define the rightful, but limited, share of Turkey's healthcare resources that can be allocated to persons with these medical needs. This treatment philosophy will be the foundation for educating and retraining physicians and nurses. It will be the guiding document for hospital policies and will shape clinic and home care services as well. It will inform lawmaking with regard to promoting access to analgesia and to orderly and respectful procedures for limiting medical care that is merely prolonging the dying process. To create this new treatment philosophy, Turkish physicians will have to accept death and dying patients as a natural life process for which medicine in its caring and comforting mode has an important role. Turkish physicians will have to stop seeing dying as a treatment failure for which we should be embarrassed or deny our engagement.<sup>14</sup>

Turkey needs clear curricular goals for teaching physicians how to treat and talk with terminally ill persons and their relatives.<sup>15,16,17</sup> To have a new kind of conversation, medical schools must teach communication skills—a subject that is often inadequately taught, if it is taught at all. Physicians must learn that it is important to disclose the risks and benefits of procedures and alternatives to patients and their relatives. They must learn how to discuss decisions to not provide therapy, such as resuscitation or chemotherapy or surgery, that is likely to prove futile.

There must be clear, legally supported statements of professional conduct. These should outline when consent is necessary and procedures for seeking consent to withhold life-prolonging care or for providing palliative care rather

than a life-prolonging treatment. They should address needless fears that providing palliative, rather than life-prolonging, care may be construed as negligence or homicide. The implications of the Turkish Penal Code should be clarified. The practice of informal and undocumented do-not-resuscitate (DNR) orders should be stopped as it invites clerical mistakes, undermines professional accountability, and evades consent.

Turkey needs to make narcotics more available to inpatients and outpatients with severe chronic pain. It should ensure that community pharmacies stock and dispense these drugs and that providers know how to prescribe them and how to empower relatives and patients to use them independently.

Home care services should be insured and capable of providing care, managing pain with narcotics at home, and teaching relatives how to care for dying persons to minimize disability and ease the burden on the family.

Research of public attitudes toward the end-of-life issues and of medical practices and beliefs is needed.

Turkey needs a public discussion about the care and treatment of people at the end of life. Dying is not a rare disease; it is part of the human condition. The public and the media must overcome their reluctance to talk about this matter for the good of dying people themselves, to address the challenges of an aging society, and to efficiently manage these medical needs and social costs in a society that has many needs.

The climate is changing for the better. The Ministry of Health has promoted a patients' rights bill and the Turkish Medical Association has emphasized patients' rights widely in its most recent regulation—namely, "The Principles of Professional Ethics in Medicine."<sup>18,19</sup> Both documents emphasize the importance of truth-telling and respect for autonomy. More recently, proposed changes to the Constitution of the Turkish Republic could, if approved by the Parliament, make it possible for individuals to make more decisions about medical care at the end of life. Turkey has made a remarkable improvement in medical technology and treatment and reached the level of most developed countries in medical knowledge. Now, these new resources must be deployed effectively around the universal human condition of mortality. This article is written to facilitate this effort.

## Notes

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