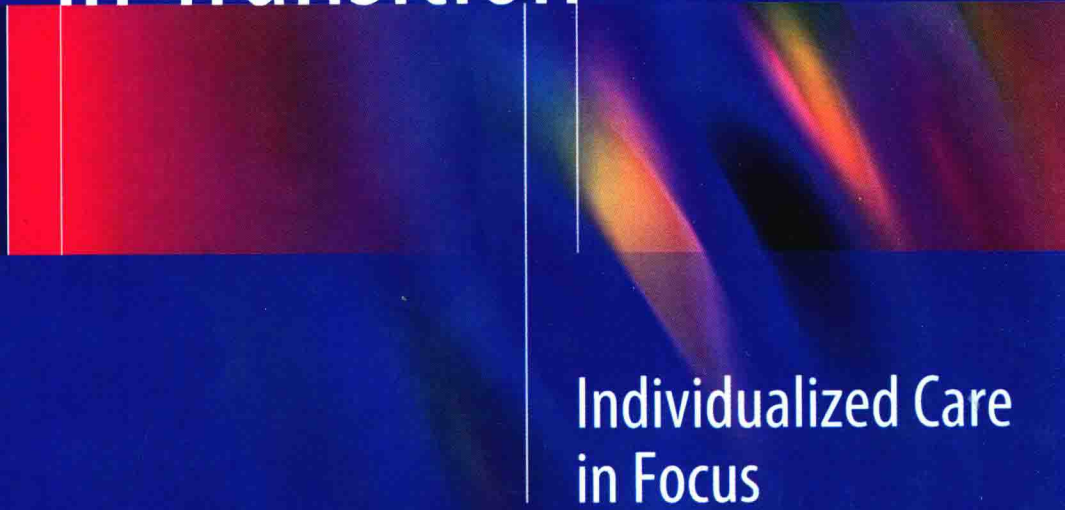


Cancer Care in Countries and Societies in Transition



Individualized Care
in Focus

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Cancer Care in Countries and Societies in Transition

This book is dedicated to Prof. Dr. A. Murat Tuncer, Rector of Hacettepe University and former Chairman of the Department of Cancer Control in the Ministry of Health, Ankara, Turkey, for his immense support, encouragement, and advice that enabled scientific and clinical collaborations in the Middle East.

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Foreword

The English Renaissance poet John Donne wrote, “No man is an island, entire unto itself.” One could further extrapolate that when it comes to confronting the scourge of cancer, no nation is an island unto itself. Cancer knows no borders—geopolitical, racial, ethnic, or socioeconomic.

With this interconnectivity in mind, in 1996 an ambitious and innovative model for constructive collaboration was born that would reach beyond national borders to provide health and hope for thousands of cancer victims in the Middle East. Almost two decades after its launch, in which I played a part, the Middle East Cancer Consortium (MECC) has helped to build bridges of understanding and teamwork between healers and scientists working together to one day defeat one of our greatest common enemies—cancer.

The treatment of cancer is often erroneously, in my opinion, referred to as a “battle” fought by cancer patients, their families, and an army of healthcare professionals and researchers. Yet seen in the context of the MECC’s mission, cancer care is also akin to a diplomatic endeavor, with education, engagement, and understanding providing powerful tools that complement the traditional weapons of medicine, technology, and research.

The statistics are shocking—every year more than eight million citizens around the globe die from cancer, and according to the World Health Organization, more than 70 % of those deaths occur in low- and middle-income countries in Africa, Asia, and Central and South America. Considering that in many of these cases cancer is diagnosed in advanced stages when survival is less likely, the demand for prevention, early detection, and treatment becomes a humanitarian imperative, not just a privilege for those who can afford it.

Cancer Care in Countries and Societies in Transition—Individualized Care in Focus offers a much-needed account of the state of global cancer care—the good, the bad, and very much the hopeful. A quick glance at the table of contents reveals chapters that read like a roster of United Nations members and makes it abundantly evident that no corner of the Earth is untouched by the ravages of cancer. The thoughtful and illuminating work of the collected authors underscores that what is of concern in the Middle East is also of concern in Africa, Asia, and Latin America. Likewise, the advances available in North America and Europe provide a cautionary framework by which developing countries can better adapt and promote lifesaving care and treatments. From the wealthiest to the poorest of nations, they all grapple with defining what is the appropriate standard for care, which varies depending upon available resources, cultural sensibilities, and environmental risk factors, to name just a few.

Throughout this wide-ranging compendium, general themes emerge: the shortage of qualified personnel; limited technological capacity; the availability and expense of specialized drugs and treatment; the merits and shortcomings of hospital versus home versus hospice care settings; patients' personal responsibility, lifestyle choices, and prevention; and palliative care, quality of life, and end-of-life planning. And all nations, regardless of their relative affluence, struggle with balancing the cost of care versus the cost of illness—there are no easy answers.

There are also some common threads of real change and hope as they relate to healthcare providers becoming empowered advocates for their patients. The expectations are high that the role of nurses in providing patient-centered and cost-effective care will continue to grow. Also evident is a better, more open communication about a disease that has long been stigmatized as if a cancer diagnosis is somehow shameful. Educating and engaging patients and their families in their care is having a measurably positive impact on outcomes, and this includes honest discussions between patients and their physicians and caretakers about end-of-life care and advanced care planning.

What is abundantly clear is that our efforts will be successful only with the concerted and continuous commitments of governments, academia, the private sector, and multidimensional organizations across and within national boundaries. Clinical professionals, scientists, educators, and social workers all provide cancer patients and their families with the support—physical, mental, and spiritual—they require to face a terrible disease that does not care about the language one speaks or the color of one's skin. In this sense, cancer is an equal opportunity waster of life.

I applaud Professor Michael Silbermann, MECC executive director and editor of *Cancer Care in Countries and Societies in Transition: Individualized Care in Focus*, for this tangible accomplishment and commitment to saving lives and making the world stronger through healthier, more productive societies. I also want to acknowledge the leadership and contributions of the US Department of Health and Human Services and its National Institutes of Health; the US Department of State Bureau of Near Eastern Affairs, Office of Regional and Multilateral Affairs, and the Bureau of Oceans, Environment, and Science; the American Society of Clinical Oncology, Department of International Affairs; the American Oncology Nursing Society,

Department of International Leadership and Development; and the European Society for Medical Oncology Task Force for Emerging Countries, Department of International Affairs.

Donne goes on to proclaim in the same work, “For Whom the Bell Tolls,” that “Each man’s death diminishes me, For I am involved in mankind.” Indeed. Not only is no one single man, woman, or child an island, we are all interconnected, and each death from cancer—no matter where in the world it occurs—diminishes us and our future potential as a whole.

Former Secretary of Health and Human Services
New York, NY

Donna E. Shalala

Preface

Overview

The burden and complexities associated with cancer care are rapidly increasing globally, and the largest proportional increases are predicted in countries undergoing epidemiological-demographic transitions [1]. Among the causes for the rising cancer burden are the increasing longevity and gradual decline in fertility that lead to enhanced aging of the populations, particularly in low- and middle-income countries [2]. Whereas in developed countries the mortality rates from cancer are slowly declining, developing countries exhibit the highest age-standardized death rates.

Emerging countries in different regions over the globe are constantly struggling with the challenge of prioritizing achievable targets in the presentation and treatment of cancer, as high-priority medical interventions have to be feasible and reasonably cost-effective at the level of primary healthcare settings.

In almost all countries surveyed in this new book, it became apparent that cancer has its own epidemiological transition: With the increasing levels of human development, cancers associated with infections and poverty (e.g., cancers of the stomach, liver, and cervix) are surpassed by those more closely associated with affluence (e.g., cancers of the female breast, prostate, and colon) [2]. Moreover, cancers vary with respect to their geographic distribution, etiology, and treatment options [3].

Although there is no universal risk factor for cancer, the predictions of the future cancer burden suggest that the annual number of new cases of cancer will surpass 20 million as early as 2025, a 41% increase from 2012 [4]. The lung, breast, and colon have lower incidence and mortality in the lowest income countries, but they are increasing due to less favorable trends in smoking than in high-income countries. Further, the rapid changes in lifestyle, e.g., obesity and sedentary life, along with newly acquired reproductive habits, i.e., decrease and delay of childbearing, are considered to be linked to the increase in breast cancer [2].

The WHO Global Action Plan for Prevention and Control of Noncommunicable Diseases (adopted on May 27, 2013) endorsed the list of essential medicines for cancer patients that can be used in primary care settings, and the only clinical

intervention included was that of palliative care [5]. The majority of countries included in this new book emphasized the lack of acceptable palliative care services in both the primary (communities) and tertiary healthcare levels (hospitals and cancer centers). In countries undergoing transition this issue becomes a cardinal one, as the majority of cancer patients are not screened and present themselves to the health system at a late stage of the disease, when the only treatment option available is that of palliation [6].

The current situation urgently calls for a much more global and regional coordination of cancer-care strategies. At present, individual countries try to implement their own cancer control plans with varying degrees of success [2].

The Middle East Cancer Consortium (MECC) is working closely with its partners in the Middle East and in other regions, worldwide, to draw attention to the increasing burden of cancer, highlighting the need to put forward the new challenges associated with cancer care in the upcoming decade. It is well recognized that there are still appreciable weaknesses in the ways that global health agencies address such challenges, fully realizing that the cancer community still has some way to go to ensure a realistic way to cope with the increasing cancer burden in the upcoming decade [7]. The current situation leads to an unacceptably low survival rate in some of the low- and middle-income countries (30–40%) as compared to those in developed countries which are today around 80% [8].

A burning issue in societies in transition refers to the unacceptable gap in adequate palliative care and access to pain relief for much of the world's population. The disparities in worldwide use of medical opioids are indeed of serious concern [8, 9]. Yet, updated reports that see light in this book reveal that considerable attempts are made to dispel the myth that effective, quality care is only achievable in high-income countries and that even in low resource settings, when appropriate programs are applied, acceptable solutions can be obtained. In order to further encourage and support such attempts, the cancer community needs to reach out to nontraditional partners via strong advocacy movement.

Recent developments have shown that by connecting the cancer community from the grassroots levels to national and regional cancer societies, opportunities can be created to see to it that more people with cancer will be treated in an acceptable manner.

Clinical cancer care plays a significant role in global cancer control. The European Society for Medical Oncology (ESMO) aims to play a pivotal role in the efforts to establish a global strategy. An important recommendation from the ESMO document on the WHO Global NCD Action Plan (GAP) at the 66th World Health Assembly in 2013 was to build upon the strengthening of primary care for NCDs as requested by GAP. ESMO experts also strongly emphasized the need and feasibility to prioritize the availability of a basic set of treatment options including palliative care interventions and improvement of access to morphine for pain relief. To achieve these goals, MECC joins ESMO, along with other global and regional agencies in leading a collaborative effort to help in the analysis and mapping of the current situation of the availability of cancer medicines globally [10].

This has resulted in the creation of an ESMO Global Cancer Task Force. The latter seeks to support the joint commitment to the regional and global cancer community and reinforce the belief that patients everywhere should have access to the best available treatment.

It should be emphasized that true knowledge brokering is not linear, but rather depends on network approaches that take advantage of what each focal point has to offer through multiple channels and intermediaries.

The populations in Middle Eastern countries, like those in other emerging countries, are expected to undergo demographic, economic, and social shifts, while their needs deserve high priority on both national and international health and political agendas. Demographic changes alone in emerging countries are projected to result in a substantial increase in cancer incidence and mortality in the two decades ahead of us.

The major obstacle to reducing the mortality from cancer is the limited socioeconomic development of these countries. Poor education of healthcare providers and the public gives rise to poor healthcare, while ill-health has an important impact on the ability to learn and to earn. Health and education are strongly influenced by poverty, which in turn reduces access to healthcare. Many factors influence access, including few primary care providers close to home. By and large, the community lacks nurses, physicians, and pharmacists and has remarkably few cancer specialists.

Therefore, even if drugs and equipment were available, they are of no value without knowledgeable health professionals, particularly oncologist who can make treatment decisions and work with a team comprised of pharmacists, oncology nurses, junior doctors, medical assistants, and social workers [11]. Thus, there is a need to increase practical responsibility for medical assistants, nurses, and community health workers. Further, there should be an incentive to practice in rural regions. It is clear that if cancer treatment were to be improved, training more oncologists must be one of the highest priorities [11].

The Critical Importance of Early Diagnosis

It is well documented that early detection generally leads to better results within the existing healthcare system at less cost and inconvenience. Hence, the education of the public and the medical community may be the single most important action to be taken if better survival rates are to be achieved. Moreover primary cancer prevention also requires public education.

Greater efficiency in detection and diagnosis should be feasible in all countries, but requires planning and individuals dedicated to developing the necessary educational tools [11].

Educating Oncologists

A partial and time-honored approach to the training of specialists is “learning by doing,” e.g., gaining experience in the practice of oncology through working with a recognized oncologist. The primary focus would be on training and knowledge assessment strongly centered on clinical care. Training could be done in any cancer center or unit, and training in a cancer center would encourage the simultaneous development of interdisciplinary teams [11].

In the long run the training and employment of social workers in disciplines involved with rehabilitation and “trackers” who ascertain the status of patients who have completed therapy should increase efficiency as well as provide improved data on survival rates.

Management of the cancer burden in low-middle-income countries requires global partnerships between cancer-care mentors from high-income countries and community health workers familiar with the local circumstances [11].

Many countries in transition have been experiencing geopolitical conflicts, domestic political turmoil, and economic recessions which detracted attention from the “slow-motion disaster”—cancer. Such neglect invites future problems, since excessive cancer burdens contribute to social instability and intersocietal insecurity. Such trends will further intensify as the population ages and with the geographical movements of populations (see chapters on Jordan). In resource-rich countries, similar problems exist in rural underserved areas that merit attention [12].

Addressing the above challenges includes strengthening the functionality of the primary care health system. The latter, in most of the developing countries, is still disorganized, dysfunctional, and inadequate in size. Therefore, local-specific solutions are in great need in several countries in the Middle East, while Turkey, Lebanon, and Cyprus have started changing this situation.

Solutions must come from community participatory processes, and international mentors must serve not only as experts but also as facilitators and students of these processes [12].

It is suggested that the focus of global health programs will be enlarged from the current emphasis on the general training of students and practitioners to include attention on service and research that can be maintained throughout faculty careers similar to the laboratory, translational, and clinical research options while emphasizing social responsibility. The involvement of communities is cardinal for the long-term sustainability of development activities [12].

The concept of a long-term mentorship program is timely with a relative minor expense. Not only will it lessen cancer burden, but it will enhance the bridging of intercultural differences and put to better use the wisdom and expertise of resource-rich countries, which eventually can transform global health [12].

Communication

Going over the chapters from the different countries, one finds out that a common barrier to good cancer care refers to lack of communication between the caregivers, the patients, and their relatives. In North America hospital-based clinicians perceive family member-related and patient-related factors as the most important barriers to goals of care discussions [13].

The fact that family members and patients have difficulty accepting a poor prognosis emerged as a key barrier to goals of care discussions which highlights the sometimes high, but understandable, levels of anxiety and denial experienced by seriously ill hospitalized patients and their families. Effective communication skills are needed to navigate these strong feelings, and yet clinicians often report discomfort in responding to the emotional reactions of patients, and learners report insufficient training to have goals of care discussions [13].

The current situation underscores and supports the need for more and better training for all clinicians in having end-of-life discussions. Therefore, communication skills, training, and tools can enhance clinicians' ability to build rapport, listen with empathy, and discuss prognosis along with its inherent uncertainty—all these will help clinicians to better support patients and families through decisions about goals of care.

Also, very important are interventions aimed at improving patient and family preparedness to engage in goals of care discussions. Such interventions may include an expanded role for interprofessional team members in facilitating communication and decision making about goals of care [13].

Factors Interfering with Cancer Care

Cancer is becoming an emerging disease of public health importance in developing countries, and this situation is worsened by wars, poverty, and major demographic changes which are so characteristic of countries in transition. Socioeconomic and cultural factors often lead to late presentation and diagnosis, more mortality, and poor follow-up of cancer survivors. The above countries/societies are known to have rich and diverse cultures where religions, traditions, and family values greatly influence medical decision [14].

In many of the countries represented in this book, many afflicted with cancer live in rural areas and in poverty. As a consequence, delays in diagnosis and poor health-care seeking behavior are common with these patients. The management of these patients is often fraught with socioeconomic, cultural, and ethical dilemmas. Among the ethical challenges are issues like: individuals' autonomy, family and community participation in care, and end-of-life issues. For the successful development of a viable and sustainable model of cancer care in resource-poor environments, these issues must be dealt with [14].

Culture and Religion

Diversity of cultural and religious beliefs of people in countries in transition, especially in Africa, Asia, and the Middle East, affects their views and perceptions of cancer care. Therefore, the healthcare systems in these regions have to take into consideration the cultural, traditional, and religious inclinations of their peoples. Unfortunately, in a large number of countries mentioned in this book, cancer is still considered to be a taboo, and many forbid the telling of a patient that he/she is dying. Also, because of the strong support provided by an extended family system, there seems to be reduced relevance for psychologists, social workers, and psychiatrists in cancer care [14].

Socioeconomic Issues

Poverty has a very serious implication for patients with cancer in the developing world. Further, many patients hide their diagnosis from family members because of financial burdens of hospital and medication payments [14].

Ethical Issues

These issues include the right to know, end-of-life decisions, death and dying, and health inequities.

The right to know. Issues related to management of information in patient receiving treatment for cancer are the center of literature on communication in cancer [15, 16]. Informing patients with cancer the truth about their diagnosis and progress, or otherwise, is still presumed harmful to the patient [6, p. vii–xiv]. The paternalistic concept in communication in which the physician was treated to act independently in the best interest of the patient is widely practiced [17]. Physicians in restrictive cultures such as those in Africa, the Middle East, and Southeast Asia remain unsupportive of full disclosure of information to patients, particularly of “bad news” [18]. This is in contrast to the attitude of physicians in more open West European and North American countries with high regard for patient’s autonomy [19]. In most populations undergoing transition in the twenty-first century, the nuclear family is still very strong, and sentiments among family members influence a patient’s choices and decisions [20].

Even in the absence of cultural restrictions, there are patients who prefer avoidance of bad news and delegate decision making to family members. The patient’s religious conviction, educational attainment, age, and psychological maturity tend to influence this attribute.

End-of-life decisions. Dying is regarded in cancer care as a natural process which is neither to be hastened nor unduly prolonged while keeping the patient as active as

possible until death [21]. The aim is a dignified death free of pain. Terminally ill patients tend to have varying degrees of depression.

Death and dying. Cultural attitude to death and dying is an important barrier to free communication with cancer patients [20]. Family dynamics and religious beliefs play major roles in shaping the concepts of death in a good number of societies in the emerging world. In a recent survey, it became apparent that many cancer patients throughout the Middle East seek complimentary therapies for a family member suffering from cancer [22]. Death and dying is a deeply emotional event in most African and Asian cultures.

Religion has dramatically different connotations in various cultures with prime drivers as history, politics, social events, and theological arguments [23]. Further, religion plays a vital role in determining patients' response to truth about their condition [24]. Also, religious, emotional, and psychological support ameliorate the impact of bad news and help patients to adjust to the reality of their situation [25].

Putting Palliative Care on the Global Health Agenda

Despite the lack of attention and investment, positive developments have occurred in promotion of palliative care in the past 15 years.

In May 2014, the World Health Assembly passed a landmark resolution urging member states to support access to essential medicines and to strengthen palliative care as an integrated component of universal health coverage throughout the life course, stating that palliative care is an ethical responsibility of health systems.

Cancer is a leading cause of morbidity and mortality worldwide; yet, despite the widespread need, only 20 countries (8.5%) have integrated palliative care adequately into their healthcare system [26].

In the greater Middle East region, a diagnosis of cancer is still mixed with social stigma, and physicians conserve a truth disclosure policy in which from one side they respect some of the historical and cultural misperceptions about cancer and, accordingly, tell the truth about cancer to one of the family members and, on the other hand, acknowledge the patient's right to know the truth and tend to disclose it for him (or her) when possible [27].

Education programs in breaking bad news are lacking in many countries. Thus, training programs are needed in this domain in Middle Eastern societies. In the Middle East, a legitimate conspiracy of silence regarding a cancer diagnosis often takes place with the aim of maintaining the patient's hope.

Iran—Anxiety and depression showed strong association with the knowledge of diagnosis of cancer [28]. And physicians disclose more frequently a cancer diagnosis to the patient's family members than to the patient himself. *There is insufficiency in communication skills* [27].

Israel—Only 63 % of physicians and 38 % of nurses stated that they always disclose bad news or negative prognosis to their patients. And patients may, on occasion, express dissatisfaction concerning their physicians' behaviors during

truth disclosure of a cancer diagnosis. Family members, in Palestine, seem to be the most important interlocutor when disclosing a cancer diagnosis [29].

Jordan—It has been stated that the Islamic attitudes and beliefs about end-of-life issues should not deter physicians from discussing such matters with the patient's family [30].

Kuwait—More than 50% of patients want to know their cancer diagnosis [27].

Lebanon—A large majority of medical students prefer to disclose the cancer diagnosis directly to the patient [31], while patients highlight the importance of communication throughout the disease trajectory [32]. Patient-family communication and truth-telling are reported as major stressors. Further, patients emphasized the importance of wording during the communication and stress the need to *move from the paternalistic approach in care provision to patient-centered care* [27].

Pakistan—Irrespective of the city of residence, the social stigma attached to a cancer diagnosis in the Pakistani society seemed to have an important influence on women's psychological well-being [33].

Saudi Arabia—Most patients prefer a family-centered model of care. However, there is a slow but steady change in public education which leads to a more cultural openness [34]. Still, educational programs for medical students lack assessment as related to communication skills related to the breaking of bad news [27].

Turkey—Studies revealed that knowing the diagnosis of cancer has a positive correlation with anxiety and depression. About 30% of cancer patients suffer from psychiatric disorders [35].

Truthful disclosure to cancer patients is not a common practice despite the potential ethical problems associated with such an approach [36]. Turkish patients suffering from cancer clearly express their desire to be told about their diagnosis and prognosis; however, caregivers do not always respect this desire. *The high incidence of psychiatric morbidity in patients who are aware of their diagnosis could be related to the deficit in physicians' communication skills* [27].

Religiosity is one of the prominent features of daily life, and the social structure is based on the importance of the family bonds instead of the individual autonomy. To date, a diagnosis of cancer in many Middle Eastern countries is associated with a social stigma and misperceptions related to its incurability; and physicians, although many of them are trained in Western countries, still practice the truth disclosure policy that respects some of the historical and cultural misperceptions about cancer; and they frequently tell the truth about cancer to one of the family members and try to conceal it from the concerned patient. The most important explanation to this conduct is maintaining the patient's psychological well-being [27]. *One thing needs attention and that refers to the physician-patient communication, since the way of breaking bad news is as important as the news itself.* Of importance is the fact that additional healthcare professionals, such as nurses, are actively involved in communicating to patients their situation. That might also contribute to a faster openness about truth-telling to patients themselves [27].

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