

CULTURE AND CANCER CARE
Anthropological Insights in Oncology

Cancer is more than a biological disease. Cultural factors are involved at every stage in the journey through cancer, from prevention to palliative care.

Based upon recent studies from the United Kingdom, Europe and the United States, *Culture and Cancer Care* examines a number of cultural themes in relation to cancer, including:

- The disparity of rates of cancer among different ethnic groups
- Culture and screening
- Breaking bad news and communication
- Cultural variations in emotional responses to cancer
- Cultural variability in cancer treatments and the influence on prognosis
- Palliative care across cultures

The book focuses on three main themes: culture, race and ethnicity and their relationship to cancer; the cultural context of sickness and help-seeking behaviour; and the shift from biomedicine to alternative forms of treatment. Throughout the book, a critical stance is adopted towards race and culture, focusing on the relation between these concepts and social deprivation.

Culture and Cancer Care is key reading for students, researchers and practitioners in oncology and palliative care, offering a clear analysis of cultural differences with regard to illness and health care. The book also offers suggestions of how ethnic disparities can be overcome both at a political and local level, through cultural understanding and culturally appropriate health education.

Simon Dein is Senior Lecturer in Anthropology and Medicine in the Centre for Behavioural and Social Sciences in Medicine at University College London. He has published a number of papers on religion and health, and is the joint Editor of *Mental Health, Religion and Culture*.

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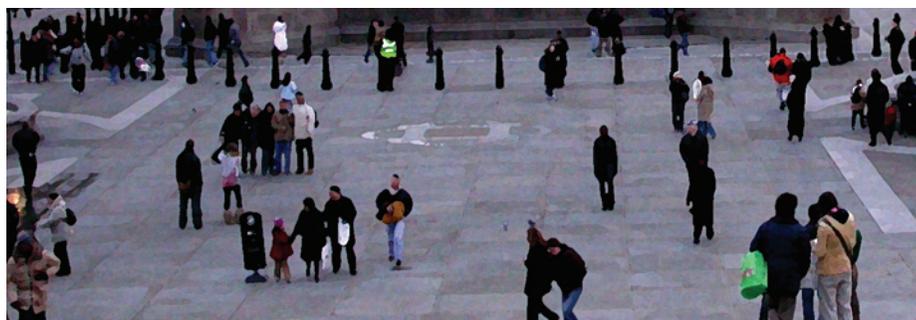
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CULTURE AND CANCER CARE
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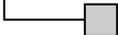


**CULTURE AND
 CANCER CARE**
**ANTHROPOLOGICAL
 INSIGHTS
 IN ONCOLOGY**

Simon Dein



CULTURE AND CANCER CARE



FACING DEATH



Series editor: David Clark, Professor of Medical Sociology,
University of Lancaster

The subject of death in late modern culture has become a rich field of theoretical, clinical and policy interest. Widely regarded as a taboo until recent times, death now engages a growing interest among social scientists, practitioners and those responsible for the organization and delivery of human services. Indeed, how we die has become a powerful commentary on how we live, and the specialized care of dying people holds an important place within modern health and social care.

This series captures such developments. Among the contributors are leading experts in death studies, from sociology, anthropology, social psychology, ethics, nursing, medicine and pastoral care. A particular feature of the series is its attention to the developing field of palliative care, viewed from the perspectives of practitioners, planners and policy analysts; here several authors adopt a multidisciplinary approach, drawing on recent research, policy and organizational commentary, and reviews of evidence-based practice. Written in a clear, accessible style, the entire series will be essential reading for students of death, dying and bereavement, and for anyone with an involvement in palliative care research, service delivery or policy-making.

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IN ONCOLOGY



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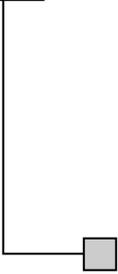
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This book is dedicated to my wife, Kalpana Dein



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Series editor's preface



In his classic work *The Sociological Imagination*, published in 1959, C. Wright Mills explained some of the processes whereby a phenomenon thought to be uniquely individual and personally bounded in character can come to be seen as a matter for wider concern – requiring the mobilizations of collective action and planning and thereby attracting the interests of the social analyst. Just such a transformation, from what Mills called ‘private trouble’ to ‘public issue’, is evident in the phenomenon of cancer in recent decades. For some time now, the experience of cancer has been shifting – from a disease to be endured by individual patients, with fortitude and a sense of fatalism, to become a site of wider public and professional concern as well as a specialist area for clinical attention. To understand such developments, we must examine the changing social construction of cancer as the ‘dread disease’ of modern culture, and move from there to an exploration of the ways in which it has been colonized by professionals, patients, policy makers and legislators. Within such a matrix, curative treatments, pain and symptom relief, and social reform are each expressed as parts of a ‘cancer world’ of increasing complexity and differentiation.

Causes and consequences are key dimensions in the social analysis of cancer. The former is illustrated in the proliferation of cancer and ‘anti-cancer’ societies since the beginnings of the twentieth century; in the rise of the oncology and radiotherapy specialisms; and in the increasing visibility of patients’ experiences of cancer within public discourse and the mass media. How politics shapes what we know and do not know about cancer is an example of the second. Meanwhile, the incidence and prevalence of cancer continue to grow apace in the poorer countries of the world, and the global ‘burden’ of the disease is a major preoccupation for epidemiologists and strategists despite a falling public health interest in non-communicable disease.

This book by Simon Dein is an important addition to the *Facing Death* series that builds on and further develops some of these issues. It invites us to explore an anthropological perspective on cancer in which all aspects of the disease – from screening and treatment through to palliation – are consistently seen through the lens of *culture*. In a compelling introduction he lays out the importance of cancer in the contemporary world – first through a fascinating case study, then in the geographic and epidemiological contexts, before moving on to the perspectives of ethnicity, poverty and gender. A series of engrossing chapters ensues. Here Simon Dein demonstrates not only the breadth of his understanding, but also his clinical awareness and his ability to write for those who are in the frontline of service delivery. His orienting framework is that of anthropology – a discipline that has been relatively under-employed in the understanding of cancer, particularly when compared to its sister social sciences, especially psychology. Using this perspective, he begins his main analysis with a discussion of the cultural and structural factors which shape the design and uptake of screening programmes; he explores the changing practices associated with communication of the cancer diagnosis; and he examines the place of religion and spirituality in cultural and personal response to cancer. His analysis also demonstrates how cancer prognoses and outcomes vary between cultural groups; how complementary and alternative treatments gain favour; and the crucial importance of cultural issues in the delivery of palliative and end-of-life care. He concludes with an assessment of how social inequalities relating to cancer can be identified and overcome.

Culture and Cancer Care adds to several other volumes in the *Facing Death* series that focus on social, ethical and moral issues in care at the end of life and which give prominence to cultural factors. It can be read alongside ten Have and Clark's collection on the ethics of palliative care in Europe¹ and a set of writings by Ling and O'Siorain on palliative care in Ireland,² as well as Sandman's volume on the good death.³ It also relates to some of the debates explored by Clark and Seymour in their sociological and policy analysis of palliative care,⁴ and provides an interesting counterpoint to the factors explored by Firth and colleagues in their work on loss, change and bereavement.⁵ Simon Dein has written a much needed book on the cultural aspects of cancer and it provides a valuable and welcome contribution to the *Facing Death* series.

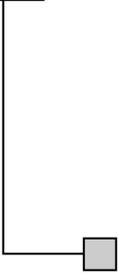
David Clark
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- 5 Firth, P., Luff, G. and Oliviere, D. (2005) *Loss, Change and Bereavement in Palliative Care*. Maidenhead: Open University Press.



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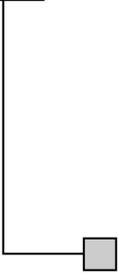
In particular, two recent comprehensive reviews of the area have stimulated my thinking about this topic: Ward, E., Jemal, A., Cokkinides, V. *et al.*

(2004) Cancer disparities by race / ethnicity and socio-economic status, *CA: A Cancer Journal for Clinicians*, 54: 78–93, and Freeman, H. (2004) Poverty, culture and social injustice: cancer disparities, *Cancer Journal Clinics*, 54: 72–7. I would like to thank these authors. Lastly, I am grateful to Professor J. Kai for his excellent book *Ethnicity, Health and Primary Care*, (2003) which has facilitated my discussion of cross-cultural communication.

The details of the case studies presented in the book, although taken from clinical practice, have been changed substantially to maintain confidentiality. All the views expressed in this book are my own.



Introduction



Salma had only been living in the UK for five years when she developed colorectal cancer. Following the death of her husband in Pakistan, she had emigrated to live with her daughter Moona, her daughter's husband Tariq and their four children. The family lived in a two bedroom overcrowded house on a run down housing estate in the North of England. She spoke and understood English very poorly. She seldom left her house and, on account of this, she mixed very little with anyone outside her own cultural group.

The diagnosis of cancer came as a shock to Salma's family. She had consulted her general practitioner on numerous occasions with abdominal pain, only to be told it was constipation and that it would resolve itself. When she was referred to the hospital, it was as an emergency, and she required urgent surgery. Her consultant was unable to communicate with her directly, and explained her 'serious diagnosis' to her family, hoping that they would translate for him. This, however, did not go smoothly. Her son-in-law asked the consultant not to disclose the fact that she had cancer to her, since in Pakistan it was common for relatives, not the patients themselves, to be given the diagnosis. The consultant was not happy to withhold this information from her and explained that she had every right to know her diagnosis. Finally, and very reluctantly, another family member explained to her that she had cancer. Rather surprisingly she seemed to accept the diagnosis very well although it was uncertain how much she really understood about the illness. Salma had always been a devout Muslim who believed strongly that her destiny was in God's hands and that whatever happened would be for the best. She was comforted by regular visits from a local imam and by her frequent prayers which gave her a sense of calm.

Her initial treatment with chemotherapy went well. She seemed to regain some strength and was able to get about by herself for a couple of months.

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But the improvement was not long lasting. She slowly became weaker, lost her appetite and vomited frequently. Further investigations revealed that her cancer had spread to her liver. Both she and her family refused further chemotherapy but were happy to accept strong painkillers. In the hope that she might be cured, her son-in-law contacted a healer in Pakistan who recited passages from the Qur'an, prepared a *taveez* (amulet) and recommended that she drank holy water.

Her deterioration continued. After a couple of weeks she required admission to her local hospice. While there, several 'problems' arose. Following an episode where she refused to undress to be examined by a male doctor, the nurses asked why she was being 'difficult'. Her admission was during the fast of Ramadan, a time when Muslims are expected to fast during the daylight hours. Although she herself chose not to eat during the day, there were several 'concerns' expressed by hospice staff about her poor food intake which was attributed to her illness. Lastly, the family felt upset since there was no private room in which they could pray. She died two weeks later. Following her death the nurses were concerned about how they should treat the body. They commented that they had never looked after a devout Muslim patient before.

The case study above illustrates a number of points related to Salma's culture: the role of the family in medical decision making; her appeal to religion as a way of coping; the use of traditional healing alongside biomedicine; her poor understanding of English; the emphasis on modesty; the importance of religious festivals; and finally a lack of medical staff knowledge about the rites of death and dying in Islam. These occurred against the background of socio-economic deprivation and poor (in this case significantly delayed) medical care. Obvious conflicts related to cultural differences are apparent.

It is important to avoid the pitfalls of cultural stereotyping, seeing ethnic minority groups as homogeneous entities, with all those belonging to a specific group holding the same beliefs and behaving in the same way when faced with similar life situations. Some members of ethnic minority groups continue to live a traditional way of life, differing little from that in their country of origin. Others have adapted to the way of life of the majority group, and have adopted its values. For these people, traditional cultural beliefs only come to the fore at certain times. For everyone, however, serious life-threatening illness, such as cancer, requires more than explanation; it requires a framework which can be used to re-establish meaning in a world shattered by illness. This framework is provided by culture and religion.

Cancer is more than a biological disease. Cultural factors are involved at every stage in the journey through cancer, from prevention to palliative care. Even the definition of what constitutes cancer varies according to the cultural context. A study among African American women with breast and cervical cancer in Atlanta elicited the belief that the only real cancer was a

late stage cancer causing death and that a non-fatal condition could not be cancer and therefore screening was of little use. For this group cancer was held to be incurable and ultimately the women believed that their destinies were determined by God. The most common explanations for cancer included a bruise or a sore that would not heal. Moreover, they held that the knowledge that one had early cancer could cause mental distress which could possibly speed up death (Gregg and Curry 1994).

In some societies there is in fact no word for cancer (Kaur 1996). Bezwoda *et al.* (1997) point out that in only three of the nine ethnic Black languages in South Africa (Zulu, Swazi and Xhosa) is there a word for cancer at all. These words do not refer to a disease that could spread to other parts of the body or requires any specific treatments to bring about cure. In Nigeria there is no common name for cancer among traditional healers. In some groups there may be several local terms connoting various types of cancer at various locations of the body.

The experience of illness cannot be considered in isolation from the cultural context in which it occurs. This is especially the case for life-threatening illnesses such as cancer where issues of meaning become paramount. Social attitudes towards cancer, how it is understood, participation in screening, health behaviour, treatments used and palliative care vary significantly across cultures. Issues related to the communication of the diagnosis and decisions about treatment (and the ethics of treating or withholding treatment) are highly variable across cultural groups. These issues in turn are related to broader ideas of autonomy, personal control (and its opposite, fatalism), explanatory models, attributional styles, ideas of personhood (including the mind-body distinction) and ultimate concerns about life and death in a given society – something that might be called spirituality.

Cancer in contemporary Western culture

Despite recent advances in the treatment of cancer, this disease remains a major world killer. The very word strikes a chord of terror in those who suffer from it. Patterson (1987) in *The Dread Disease: Cancer and Modern American Culture* points out the contemporary deep-seated fear concerning cancer in contemporary American culture, a fear which emerged during the second half of the nineteenth century. Although about 50 per cent of cases of cancer are potentially curable, lay people in both Western and non-Western cultures still have a universal dread of cancer. In most instances the disease remains highly stigmatized.

Although there is a large literature examining the causes, symptoms and treatments of this disease, there is relatively little work which looks at how attitudes, understandings and responses to cancer vary across cultures. The contemporary literature on cancer can be divided into three types: bio-

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medical; self-help books including those on complementary and alternative medicine; and first hand accounts of cancer by sufferers themselves. There are many books written by authors grounded in a biomedical tradition discussing the facts about the various types of cancer and their treatments (by radiotherapy, chemotherapy and surgery). These are useful for cancer patients who want biomedical information about their cancer. Books about complementary and alternative treatments for cancer appear to be flourishing (e.g. Hay 1989; Siegel 1993). Much of the market is monopolized by the so-called 'self-help' books, offering advice about coping with the disease and how complementary or alternative therapies can be helpful. Often these books talk of overcoming cancer through willpower or major lifestyle changes.

Since the mid-1990s there has been a new genre of writing – books written by patients and their relatives about the experience of cancer. Some of these, such as *Teratologies* (Stacey 1997); *The Wounded Storyteller* (Frank 1995); and the recent *Stranger in the Village of the Sick: A Memoir of Cancer, Sorcery and Healing* (Stoller 2004) are written by social scientists who happen to have cancer themselves and discuss contemporary cultural and anthropological themes while describing their individual experiences of cancer. They provide a critique of Western biomedicine's conceptualization of the body as separate from the self or person, whereby the patient's illness is reduced to a 'case' that can be quantified in terms of its symptoms and modes of treatment.

Although *Culture and Cancer Care* is exemplified by individual case studies, much of the information presented below is epidemiological, using data from the literature which examines the relationship between cultural factors and various types of cancer across a number of cultural groups. Unlike other recent books which have focused on cultural aspects of cancer (e.g. Moore and Spiegel, 2004, *Cancer, Culture and Communication*, which emphasizes how cultural contexts influence cancer communication), this book integrates anthropological ideas into oncology and is as much a critique of essentialist notions such as culture, race and ethnicity in the oncology field. A central theme of this book is to discuss cancer inequalities in relation to the unequal distribution of power and resources within societies and its relationship to wider social issues such as racism. As such, it deploys a political economy approach – one that emphasizes the consequences of power and resources for health and mortality.

Geographical focus

The literature discussed in this book derives from North America, Canada, the United Kingdom, Europe and Australia although the majority of studies quoted are from the UK and USA. Despite the fact that the demographic

structures of the UK and USA are different, both have racial and ethnic minority populations who have poorer health than the general population, including increased rates of some types of cancer and poorer prognoses.

There are significant differences between the healthcare systems in the latter two countries, which influence how cancer patients are treated and the eventual outcome. In the USA there is a liberal healthcare system whereby the majority of the citizens have obtained healthcare by their own means, especially by subscribing to private insurance. Coverage is usually employer based, although 40–50 per cent of the funding derives from government programmes such as Medicare or Medicaid. Many people in this situation are not insured or are underinsured (about 44 million people) and are denied high quality medical care. Speciality and tertiary care dominate the US system, which is highly influenced by the principles of entrepreneurship and the free market economy.

The American situation is to be contrasted with the British state-run system of healthcare, whereby its cost is paid for out of taxes and is free at point of use for British citizens and those from the EEC. Healthcare is seen as a public service and coverage is universal. In the UK system there is an emphasis on primary care providers (General Practitioners or GPs) at the point of access. The role of private providers is limited. These different systems significantly influence access and quality of cancer healthcare among different sectors of the population.

What is cancer and what causes it?

Cancer is the disordered and uncontrolled growth of cells within a specific organ or tissue type. Most cancers begin in a single site such as breast, lung or bowel. If untreated the cancer grows and can invade normal tissues causing extensive tissue destruction with resulting functional damage. It may also spread through the blood stream and lymphatic system to produce secondary growths termed metastases. These may themselves cause profound damage and are often life threatening. We are still ignorant of the mechanisms causing metastases.

Factors known from epidemiological studies to be causally related to the development of cancer include environmental factors such as smoking (lung, larynx, pancreas, mouth, kidney and bladder) and diet (fat intake and breast cancer). Other environmental factors derive from working in specific occupations (e.g. dye workers and bladder cancers, asbestos workers and mesothelioma). Age is a major risk factor for many cancers (lung, oesophagus, stomach, pancreas, prostate, breast and uterine). Greater age at first pregnancy has been shown to increase the risk of breast cancer. Up to 10 per cent of common cancers, particularly those of breast, ovary and large bowel, occur in familial clusters and are related to a familial gene. There is some

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evidence that viral infections may cause cancer (nasopharyngeal cancer in China and the Epstein Barr virus, papilloma virus and cervical cancer). Radiation may be responsible for the development of thyroid, leukaemia, lymphoma and lung cancer. Souhami and Tobias (2002) have provided an excellent overview of this area.

A major public health problem

According to the World Health Organisation (Lopez 1990; World Health Organisation 1991), in 1985 nearly 50 million people died worldwide. Cancer was the cause of 10 per cent of deaths, 23 per cent died of circulatory diseases and 5 per cent died of chronic obstructive lung diseases. The largest proportion of deaths were caused by infectious and parasitic diseases (36 per cent). However this situation is likely to change rapidly with progress in treating infectious diseases. A projection of mortality and the causes of death indicate that in 2015 the major causes of death will relate to non-communicable diseases. It is estimated that cancer and circulatory diseases will account for 54 per cent of all deaths in this year (Bulatao and Stephens 1991). The major increases will occur in developing countries. These figures do not take into account the large numbers of AIDS sufferers of whom between 10–40 per cent develop malignant tumours.

Lung cancer and AIDS are already major causes of death worldwide and it is likely that these two diseases will continue to be major killers in the early part of the twenty-first century (Lopez 1990; World Health Organisation 1991). Lung cancer is emerging as a major health problem in many developing countries, especially Africa, and is the most frequent cancer worldwide (Parkin *et al.* 1988; Ferlay *et al.* 2004). This is as a result of increasing tobacco use. Although potentially preventable and dependent on lifestyle, high mortality rates spread from industrialized countries to the rest of the world. This disease is essentially incurable and major resources will be required to adequately palliate its symptoms. Of the estimated 10 million tobacco related deaths in the year 2015, about three million are expected to occur in China alone and almost one million of these deaths will be from lung cancer (Stjernsward and Clark 2003).

Approximately 60 per cent of the world's new cancer patients occur in developing countries and at least 80 per cent of these are incurable at the time of diagnosis. These figures have implications for both resources and treatments. About 75 per cent of total healthcare spending, public and private, in developing countries goes on curative efforts mainly in hospitals which are located in urban areas, despite the fact that most of the population resides in rural areas. There is a need for a comprehensive approach to the development of a coherent prevention, treatment and care policy for those with cancer and AIDS related cancer, with perhaps greater emphasis being

given to prevention and palliative care rather than curative efforts. These trends are of great interest and significance in themselves, and will provide much needed data for cancer epidemiologists and health providers. In this book however the focus is on cancer in developed countries.

The epidemiology of cancer in the USA and UK

Epidemiology is the study of the distribution, determinants and frequency of disease in human populations. Epidemiologists use a number of terms to describe rates of illness. The term 'incidence' refers to the number of new cases of illness which occur in a population in a defined time period. It is usually expressed as a percentage, or as a number of cases per 1000 or per 100,000 people in the population. The term 'prevalence' refers to the total number of existing cases of a disease at that time divided by the number of the population at risk.

Cancer is a common disease in the UK. As a cause of mortality it is second only to cardiovascular disease. It is the cause of 26 per cent of all deaths in the UK (Office for National Statistics 2002) and is diagnosed each year in one in 250 men and one in every 300 women. Over the age of 60, three in every 100 men develop the disease each year (Souhami and Tobias 1998). Approximately one in three people will develop cancer in their lifetime (Cancer Research UK 2004).

One in four deaths in the United States is attributable to cancer, and one in three Americans will eventually develop some form of cancer (Haynes and Smedley 1999). One half of new cases of cancer occur in people aged 65 years and over (US Department of Health and Human Services 2000). In 1999 cancer accounted for 440,000 deaths among older persons in the USA and is now the leading cause of death for Americans aged 60–79 years, and the second leading cause of death for those over 80 years (Jemal *et al.* 2002). A collaborative report between the American Cancer Society, the National Cancer Institute, the National Institute on Aging and the Centers for Disease Control and Prevention (Edwards *et al.* 2002) notes that cancer has surpassed heart disease as the major killer of Americans under the age of 85 years and that it accounts for one in every four deaths. The report estimates that the total number of cancer cases can be expected to double by 2050 if current incidence rates remain stable on account of the ageing structure of the US population.

Cancer in ethnic minority groups in the USA

According to the latest estimates, roughly one in every three people in the United States belongs to a racial and ethnic minority group. Latinos (the