Anthropology is the study of mankind in its widest context. The field can be divided into archaeology (the investigation of human cultures of the past through the recovery of material remains), material culture (man’s material environment), and social anthropology (the study of man’s social environment including institutions such as kinship, economics, marriage and religion). Medical anthropology is a branch of social anthropology and refers to the study of social and cultural dimensions of health, sickness and medicine. This book specifically addresses medical anthropological issues. However, the field of oncology cannot ignore the findings of archaeology, which indicate that cancer is indeed found in ancient civilizations (Roberts and Manchester 2001). Although we are limited by the fact that all that remains of ancient bodies are the skeletons (apart from rare mummified specimens), it appears that diseases such as osteosarcoma and multiple myeloma existed in early societies. For instance, a humerus from Iron-Age Switzerland displaying the pathological findings of osteosarcoma and evidence of multiple myeloma was found in an adult female skull in Caudiville, Peru dating back to 500 AD.

Medical anthropology has developed significantly since the 1980s, with anthropologists taking a particular interest in the specific domain of sickness. Anthropological approaches emphasize three main tenets: first, anthropology emphasizes holism. This is the idea that any social institution cannot be understood in isolation. Each social institution interrelates with other social institutions. For example, sickness can only be understood by taking into account ideas about kinship, economics and religion and is related to wider concepts of autonomy, the self and misfortune in general. Helman (2001: 50) states how ‘Anthropologists have pointed out that any society’s healthcare system cannot be studied in isolation from other aspects
of that society, especially its social, religious, political and economic organisation.

Second is the idea of relativism. Each cultural group has their own specific ways of understanding a cultural phenomenon. We must learn to understand sickness from their own point of view and move away from ethnocentrism (seeing something from our own culture’s perspective). Even biomedical knowledge, the dominant medical system in Western cultures based on scientific rational empiricism, itself is culturally constructed. Despite the fact that biomedicine claims to be universal, various studies point to the fact that there are significant differences in the types of diagnoses given and the treatments prescribed between different Western medical systems. Terms such as ‘family’, ‘religion’ and ‘medicine’ may have specific meanings for cultures and cannot be taken for granted. Understandings of specific diseases such as cancer cannot be divorced from the wider cultural perspective in which suffering is understood.

Third, beliefs may not reflect actions. Ideas about treating illness and lay explanatory models are shaped by contingent circumstances and forms of practical ‘reasoning in action’ (Lambert and McKevitt 2002). A person may believe one thing and do another. Medical anthropologists are interested not just in what people say about sickness but what they actually do in practice. Methodologically, there is an emphasis on participant observation – direct observation while participating in a study community. Medical anthropologists observe real life scenarios of healing and in the process attempt to understand how groups of people engage in medical decision making. This is directly relevant to oncology. For instance, women may state specific negative beliefs about screening for cancer yet still partake in the screening process. A medical anthropologist would attempt to explain this discrepancy.

A number of themes are commonly discussed in contemporary medical and psychiatric anthropology: disease and illness; health, culture and ethnicity; the political economy of health; explanatory models; metaphors of illness; the self and agency; narratives; and the cultural construction of emotion. These are discussed below, beginning with the distinction between disease and illness.

Disease and illness

Medical anthropologists make a distinction between disease and illness (Kleinman 1990). The former refers to pathology in the cells, tissues and organs. The latter refers to the social and psychological response to the underlying disease and also the ways in which it is conceptualized and understood. The two are different. This book focuses on illness. The social and psychological response to cancer and the ways in which it is understood are influenced by the cultural context. It is possible to have a disease without
illness. For example, a person may be ‘harbouring’ an early cancer and not have any symptoms. The finding of early asymptomatic cancer is the aim of cancer screening. On the other hand, the person may have a belief that they have cancer but there is no cancer found. This person has an illness but not a disease.

**Culture, race and ethnicity and anti-racism**

Culture, race and ethnicity are terms commonly used in the health literature, often in confusing and contradictory ways. The term ‘culture’ is probably the most commonly used concept in anthropology, although there is much debate as to the exact meaning of the term. Definitions of culture vary in emphasis between the humanistic – culture is what a person ought to acquire in order to become a fully worthwhile moral agent – and the anthropological sense in which the world is divided into different cultures each with its own worth. Each particular person is a product of a particular culture.

The term must be distinguished from race: a framework of ranked categories based on biological characteristics which divide up human populations and society. This concept was formulated in a time of social Darwinism and is now discredited as a biological descriptor. The term has been attacked and undermined by advances in genetics. In contemporary writings the term race is virtually indistinguishable from ethnicity and the concept of race is slowly being redefined as a cultural and socio-political construct. Despite much theoretical critique, many researchers have been convinced of the continuing potential of the term to explain genetic differences in rates of some diseases such as hypertension (Baker et al. 1998).

In much of the research addressing health inequalities, colour may be an important indicator of historical and current discrimination. However, health inequality is likely to be a result of social factors including poverty, diet, employment, etc. Only for a few specific genetic diseases will biological factors be important causes. The example of the haemoglobinopathies such as sickle cell disease may be cited here. The role of biology has far too often been implicated as an explanation for racial differences in disease rates.

Another term commonly used in the literature is ‘ethnicity’. The term is neither simple nor precise but implies one or more of the following: shared origins or social background, shared culture, and traditions that are distinctive, maintained between generations and lead to a sense of group identity and common language or religious tradition (Senior and Bhopal 1994). It emphasizes shared history, geographical origins, language, diet and other features.

A large social anthropological and sociological literature exists about ethnicity and there is little consensus about the categorization of ethnicities. Macbeth (2001) argues that accurate definitions of ethnic groups are
impossible on account of the absence of meaningful boundaries but nevertheless some factors which can be called ethnic are highly significant to health experience. For second generation people who were born and educated in the UK and have British accents, the ethnicity definition is very problematic. For the same individual, different ethnic identities come into play at different times and in different contexts. The term is not politically neutral and can serve a similar function to race in the portrayal of cultural difference as deviant or pathological. There is thus a continuing need for the concepts of race and ethnicity to be strictly demarcated and used precisely. One possible advance as Bhopal (2001) argues is to replace the terms race and ethnicity with the term ‘identifiable populations’.

The ethnic terms ‘White’, ‘Black’ and ‘Asian’ are commonly used in the UK, whereas ‘White’, ‘Black’ and ‘Hispanic’ are used in American articles. The term Asian in the USA refers to Chinese and Japanese whereas in the UK it refers to those from the Indian subcontinent. From April 1995 the British Department of Health has required hospitals to collect data on the ethnicity of patients and has deployed categories based on census data. This in turn may help to further understand the often complex relationships between ethnicity and cancer incidences and mortality.

Over time, members of ethnic minority groups may learn to become a member of the host culture, a process referred to as acculturation. The term is commonly used in the health literature, although it is seen by anthropologists and sociologists as being an outdated concept which has undesirable connotations. Some degree of acculturation may in fact occur prior to emigration. In the past the assumption was held that those who did not change to majority cultural values were being ‘inconvenient’. The term does not allow for the change which the majority culture undergoes through contact with minority cultures. Following immigration, ethnic minorities may in fact more strongly adhere to their traditional cultural practices to maintain their self identities and this may occur especially at times of serious illness such as cancer.

Within any ethnic minority group, levels of acculturation in relation to health and illness may differ in terms of fluency in the national language and how au-fait an individual is with the majority culture’s conceptualizations of health, illness and healing. As Ahmad (1993) notes, there is a difference between being aware of the health beliefs of another culture and actually sharing these beliefs. For example, a member of an ethnic minority group may speak English fluently and adopt certain practices of the majority culture, but refer to the beliefs of their ethnic group when conceptualizing health. In the UK some ethnic minority communities may maintain distinctive definitions of illness and traditions of healthcare (Bhopal 1986; Krause 1989). Their health beliefs and knowledge may be incongruent with that of the health services (Donovan 1986). Healthcare beliefs, however, change as younger generations are educated in the same school curricula worldwide.
The factfile approach to culture

One approach which has frequently been deployed in writing about ethnic minorities is the ‘factfile’ approach, which provides a description of the core beliefs and practices of a given cultural group. The factfile approach offers cultural and religious knowledge as a way of solving professional and institutional difficulties in meeting the needs of ethnic minority patients (Gunaratnam 1997). It argues that in order to improve healthcare, minorities should be re-socialized through health education, while at the same time health and service providers must be equipped with the tools of cultural understanding. Such factfiles have been used by palliative care workers and include detailed information about death, dying and bereavement (e.g. Firth 1993a; Neuberger 2004).

Factfiles range in content from well researched and sensitive material (Henley 1987; Neuberger 1987) to simplistic approaches (Bal and Bal 1995). Populations are typically categorized according to beliefs and practices. For instance, Alix Henley provides a list of the cultural customs of different ethnic groups. This approach is problematic in a number of ways. Ahmad (1996: 195) argues that these factfiles or checklists pathologize culture—minority health problems are seen to arise from their own cultural practices. There is a politics of victim blaming:

In the guise of cultural understanding one is frequently offered a catalogue of checklists of cultural stereotypes which are regarded as essential characteristics of particular racial/cultural types and which signify the deviance and the peculiarities of minority cultures to the normality of ‘British’ culture.

Culture becomes reified and seen as something which is static, not as something dynamic and negotiated. Factfile approaches provide, as Gunaratnam (1997) argues, snapshots of cultural and religious practices. This approach neglects the historical factors which influence cultural narratives and mystify the social production of culture. Factfile approaches neglect the power relations which continuously destabilize cultural practices.

Factfiles can stereotype people from a different culture, which leads to expectations about how someone from a certain culture should behave. They may detract from individual subjectivity. They privilege and separate cultural processes from individual and subjective elements. Within a given cultural group there may be much inter-individual variation of what people do in relation to health. People do not always behave in terms of their culture. For instance, non-compliance with medication may be seen to be based on cultural beliefs, whereas it may in fact be an idiosyncratic choice.

In summary, factfile approaches are part of the professional discourse on multiculturalism but at the same time use conceptualizations of cultural and religious practices which are silent about racism and can legitimate
discrimination (Gunaratnam 1997). Cultural analysis may divert from the more important issue of demonstrating how racism is a common experience of all non-White people, involving them in social disadvantage resulting in higher rates of illness than White people. Ahmad (1993: 2) argues:

in this perspective, racialised inequalities in both health and access to healthcare are explained as resulting from cultural differences and deficits. Integration on the part of minority communities and cultural understanding and ethnic sensitivity on the part of the health professional then become the obvious solution. Personal and institutional racism and racial discrimination have no part in this equation.

Is culture at all a useful concept when examining ethnic minority health? It is a very nebulous concept, which is often criticized as being a reification and simplification of perennially shifting experience, forcing a picture of predictability and order onto what is essentially chaotic. However, having said this, it is an important variable in the perception, experience and expression of suffering and therefore a useful term. There are very real differences between cultural groups. However people may often see themselves as being part of a wider group than their ethnic group. For example, many south Asians define their core identity as Muslim as opposed to relating to nationhood or being non-White. Also there may be broad cognitive structures which differentiate cultural groups and determine how they respond to their (often disadvantaged) position. People actively draw on elements of their culture to manage life stresses. Culture influences, rather than determines, the way people live. It provides ideas about the appropriate behaviour in a given situation, their response to illness and to medical ideas about treatment.

The problem with culturalist explanations of health and health behaviour

In the health related literature on ethnic minorities, there is a strong tendency for explanations of variations in health status in different ethnic communities to be based on oversimplistic culturalistic explanations. These culturalist explanations account for differences in the healthcare needs of Black and ethnic minority people in terms of cultural variations and ignore social and economic deprivation as being causally related to the development of certain illnesses. For instance, rickets among Asian groups is held to relate to the ‘Asian diet’ and lack of sunlight. The fact that many Asians live in inner city areas with limited access to park space and limited mobility on account of a real fear of racial discrimination is not taken into account. Socio-economic factors are ignored.

The term socio-economic status (SES) is a broad term referring to economic and social circumstances. It is difficult to measure directly and proxy
measures, such as occupation of head of the household, are generally used to indicate different socio-economic groups. The distinction between what is ethnic and what is socio-economic is far from clear in minority groups (Nazroo and Davey-Smith 2001). Although differences in socio-economic status or class may be more important than ethnic or cultural differences in explaining ethnic minority health statuses, both culture and ethnicity are still important. In this respect Smaje (1995: 124–5) argues for the importance of ‘more refined approaches to the dynamic interactions between culture, socio-economic status and health experience’.

Similarly Ahmad (1996: 215) calls for more sophisticated understandings of the concept of culture:

In studying health and illness among minority ethnic communities, the cultural context is of crucial importance. However to be of value, either in explanatory or practical terms, ‘culture’ needs to be recognised as a context, itself flexible and contested, interacting with, shaping and shaped by other social and structural contexts of people’s lives. Cultural norms, themselves contested and changing, represent flexible guidelines within which behaviour is negotiated rather than an independent variable which is solely responsible for determining behaviour. Recognising this will be an important development in moving towards research on health and social care of minority ethnic communities which is of value for both its academic and practical contributions.

What relevance does the above hold in relation to cancer? The terms race and ethnicity have little explanatory value in themselves. Consider the question of breast cancer screening. Is the service being accessed by all racial or ethnic groups? If not, why not? Categories used such as South Asian or Black may be crude and the programme may be accessed well by South Asians generally, but Bangladeshi Muslim women may have poor attendances. To answer this question, the South Asian population could be subdivided into Bangladeshi, Indian and Pakistani. However, when data is required for the development of a new policy, to effect change or evaluate the effectiveness of treatment, there is a need for a much deeper understanding (Bhopal 2001). For example, in order to understand why breast screening is taken up less by some racial/ethnic groups it is important to ask about causality issues, religious views, language of communication, beliefs about prevention and understandings of cancer. The attitudes and behaviours of service providers which might lead to racial discrimination are also crucial to further understanding. The terms ‘race’ and ‘ethnicity’ cannot answer these questions and the ‘Black box of race’ and ethnicity needs to be opened (Bhopal 1997). The terms may be markers or indicators of problems which merit further investigation.
The political economy of health and illness

The literature on health and ethnicity, including that on ethnic differences in cancer, often treats ethnicity as a ‘social fact’ representing a real and significant dimension of social experience. Field et al. (1997: 21) have argued that the intention is to establish interrelationships between these different aspects of social reality in order to explain differences in health status and health outcomes. In this ‘paradigm’, explanations of ethnic differences in mortality and illness behaviour are largely concerned with ‘real differences’. This approach is limited to the analysis of patterns of behaviour and of the broad social factors which shape individual behaviour.

What is ignored in this approach is a consideration of the unequal distribution of power and resources within societies and the conflicts around competing interests. In the political economy approach in anthropology (Singer and Baer 1995), explanatory priority is given to the material conditions mediating differences in health and mortality between different groups. This perspective emerged in the early 1980s and adopts a holistic understanding of the causes of sickness. It focuses on the interrelationship of medical systems with political structures, the contested character of provider/patient relations, and locates the patient’s/sufferer’s experience in political and economic contexts. Beyond underscoring the consequences of power and resources for health and mortality, this approach examines the ways in which power is maintained through the actions and ideas of social groups, such as doctors. In the biomedical approach, with its emphasis upon individuals as the site of disease and upon medical intervention, attention is deflected away from the fundamental underlying social and economic inequalities which are a significant cause of health inequality. A full understanding of health inequalities necessitates an appreciation of these power structure differentials.

Lay theories of health and illness

How a person explains a disease is likely to influence how they respond to it and what they do about it. In many parts of the world where people lack biomedical knowledge, disease is explained in terms of lay theories. There have been several attempts to classify lay illness aetiologies, especially in non-Western societies. For instance, Foster and Anderson (1978) differentiate between personalistic and naturalistic systems. In the former, illness is due to the purposeful active intervention of an agent, such as a God or a ghost. In naturalistic systems, illness is explained in impersonal, systemic terms due to natural forces or conditions, such as cold, wind or damp or disequilibrium within the individual. Helman (2001) describes how lay theories can be divided up into aetiologies in different domains. These domains
may vary in emphasis between different cultural groups. Sickness may be ‘caused’ by various disturbances in:

1. The individual, e.g. genetics, smoking, diet;
2. The natural world, e.g. heat, wind, lunar influence, toxins, viruses;
3. The social world, e.g. witchcraft, sorcery, evil eye;
4. The supernatural world, e.g. gods, spirits.

In most cases lay theories of illness aetiology are multi-causal. Kleinman (1980) describes a framework for eliciting patient’s ‘explanatory models’ about specific diseases. Explanatory models are sets of beliefs or understandings that specify how an illness episode is caused, its mode of onset and symptoms, pathophysiology and its treatment. These are formed and employed to cope with specific health problems and therefore need to be analysed in that concrete setting (Dein 2004a).

Explanatory models are attributes of individuals. They draw on shared cultural knowledge but remain at least partially idiosyncratic and situational. They are frequently fragmented, not fully worked out and often change and are influenced by the individual’s illness experiences and treatments. They are related to help-seeking behaviour in complex ways. They provide patients with the information they need when choosing and evaluating medical interventions, communicating with others about sickness and making their own distress recognizable to them. Being pragmatic they are strongly orientated to making statements about illness causation. Patients and physicians may hold different explanatory models of illness deriving from their differential knowledge of medicine and this fact might result in problems in doctor-patient communication and interaction. These explanatory models may relate in specific types of health seeking behaviour and should be elicited from patients and their families so that physicians can understand specific illness behaviours.

Beliefs about cancer may influence the perception of risk of developing the disease, participation in screening programmes, emotional responses to the disease, doctor-patient relationships and decisions about treatments, and are therefore of importance to oncologists and other health professionals working with cancer patients (Cooley and Jennings-Dozier 1998). It is important to differentiate lack of biomedical knowledge from lay beliefs. A person may have little understanding of the factors causing cancer, or on the other hand, may hold lay beliefs which differ significantly from biomedical understandings.

Western societies predominantly stress factors within the individual or natural world, whereas explanations involving the social world or supernatural worlds are still commonplace in traditional societies, where religious worldviews prevail. For instance, in one study, Latina women in southern California were more likely to attribute breast cancer to ‘sinful’ behaviour (alcohol and drug use) than Anglo-American women (Chavez et al. 1995). It
appears that modernization and globalization might be eroding these traditional belief systems, although indigenous people may still maintain them to a greater or lesser degree (see Box 1.1).

Explanatory models can have practical implications. In some instances holding idiosyncratic beliefs about cancer may inhibit the use of biomedical treatments. A study of disadvantaged Hispanic women in the Bronx, New York, found that 58 per cent believed that surgical treatment of breast cancer would cause it to metastasize. Holding such beliefs might prevent women from undergoing potentially curative treatments such as lumpectomy (Morgan et al. 1995).

### Eliciting explanatory models about cancer

Lay beliefs about cancer may be elicited in four major ways:

1. Structured interviews using rating scales;
2. Ethnographic interviews;

#### Box 1.1 Explanatory models of sickness among the Navaho

Among the American Navaho Indians, serious illness such as cancer is attributed to a number of causes including: soul loss; intrusive objects; spirit intrusion or possession; breach of taboo or witchcraft/sorcery. Religion permeates all aspects of life (Kittler and Sucher 1998). Healing is considered sacred work and is not considered effective without considering the spiritual aspect of the individual. Use is made of traditional healing and biomedicine simultaneously.

In one study (Diversity Resources Inc. 2001) 70 per cent of Navahos used traditional healers and 28 per cent of Indians living in Milwaukee and the San Francisco Bay area continued to use traditional healers. It is seen as acceptable for a person to consult a Navaho diagnostician to identify the cause of a disease and arrange a ceremony to eliminate that cause, as well as to consult a physician to alleviate the symptoms of the disease. Traditional healers may burn herbs in an abalone shell to purify people and places in a ceremony called smudging. Sickness of any degree is seen to affect the whole community and healing is a communal affair. In traditional Navaho medicine, illnesses are classified by the agents believed to cause them or the ceremonies used to cure them rather than by parts of the body affected. Cancer may not be discussed publicly to avoid ‘wishing’ it on others (Glanz 2003).
A number of quantitative scales have been devised to measure beliefs about cancer including the Black American (American Cancer Society 1981), adolescent perception (Price et al. 1998) and the Chinese Beliefs Questionnaire (Dodd et al. 1985) based on Kleinman’s idea of explanatory models. These scales measure attitudes towards and beliefs about cancer, cancer prevention and cancer treatments within a variety of age groups and ethnic populations. They vary in their validity and reliability (Nielson et al. 1992). They are generally quick and easy to administer and can be analysed using routine statistics. However, like most structured questionnaire studies, they impose definitions on informants (such as perceived causes of cancer) without allowing for the informants own (or emic) definitions of what is going on. A good example of the use of quantitative methodology is a study which examined the psychosocial factors influencing attendance, non-attendance and re-attendance in a breast screening programme in an inner city area in the UK (Fallowfield et al. 1990). This study deployed quantitative rating scales, devised by the researchers who examined health beliefs, knowledge about cancer and attitudes towards breast cancer screening.

In ethnographic interviews the researcher elicits an in-depth account of how informants themselves understand a particular disease ‘the essential principle in developing an understanding of a person’s beliefs is to try and understand the world . . . through that person’s eyes’ (Sensky 1996: 64). The interviewer does not pursue any a priori assumptions and attempts to move outside any ethnocentric views. Unlike quantitative studies, qualitative interviews are carried out on small numbers of informants to obtain in-depth information. They are analysed by content analysis, whereby themes are drawn out from the data. Data from qualitative interviews can be used to devise quantitative scales.

Semistructured interviews can be used to elicit informants’ models of illness. Here the interviewer asks about a range of topics which informants can elaborate upon. A study by Gifford (1994) examining 20 middle-aged working-class women of Italian Australian descent, looked at understandings of cancer using in-depth semistructured interviews. This study is illustrative of studies in the literature which deploy qualitative methods and demonstrates the different meanings one group holds about cancer. Cancer was attributed by informants to the menopause where blood no longer flowed and therefore became putrid leading to cancer. The word cancer was used reluctantly by these women. Instead they used the euphemism ‘that terrible disease’. Included in the rubric cancer were a number of tumours both benign and malignant. Only malignant tumours were held to be fatal. By contrast benign tumours were cancers that could be cured and were described as being ‘little, centred in one place, not having roots and not
being in the blood’. Malignant tumours were held to have roots and spread through the blood. On account of this, cutting out the tumour could not be successful. The perceived prognosis for this malignant tumour was almost inevitably death.

Several women held that if a doctor discovered a malignant tumour, the woman should not be told for fear that death could be hastened. A third group of conditions were not considered to be tumours but could turn into tumours if not treated. This group included fibroids, cold sores, inflammation and cysts. Generally cancer was held to be asymptomatic and was frequently discovered too late when the roots had spread. Other proposed causes of cancer were sorrow, unhappiness and living an unnatural life.

Another qualitative method is the use of focus groups. Here a group of 6–12 participants are interviewed together. Use is made of the group dynamic to focus on a particular topic, for instance health beliefs. Participants may be asked to discuss various audiovisual media, such as leaflets or videos. Dein (2005) has deployed this methodology to understand attitudes towards cancer among elderly Bangladeshis in London (see Box 1.2). In this study informants held cancer to be incurable and a disease that doctors could not do much about. It is not surprising that this population is reluctant to seek help for cancer.

Bangladeshis aside, there has been little work examining knowledge and understandings of cancer in the UK among other ethnic minority groups (Dein 2004a). In one study of cancer beliefs among the White majority

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**Box 1.2 Attitudes of elderly Bangladeshis to cancer: focus group study**

*Cancer is invariably fatal.*

‘If you have it you will die, that’s certain. It’s always fatal’ (male, 65 years)

*There is nothing that doctors can do about cancer.*

‘I don’t think any treatment helps cancer. Once you have it, there is nothing you can do. It will kill you.’ (male, 60 years)

*Cancer is a horrible death.*

‘I knew of one man who had cancer in Bangladesh. He went yellow and lost weight. He had a lot of pain and died soon after. It was a horrible death.’ (male, 56 years)

*Doctors are not good at picking up cancer.*

‘Doctors do not treat us well, they do not respect us. They do not examine people properly and I don’t think they can pick up cancer.’ (woman, 51 years)
community in the UK, the perceived causes ranged from moral wrongdoing to contagion (Box 1984). Other perceived causes include trauma caused by divorce or separation (Bhopal and Rankin 1996). In Baxter’s (1989) study, there was a clear lack of knowledge about cancer especially among non-English speaking and older people. Of interest, the beliefs of the minority groups did not differ widely from those of the majority White population. Cultural beliefs related to sexuality may influence treatment decisions. West Indian women in the UK are reluctant to have a hysterectomy, since they consider that menstruation is a cleansing act clearing the body of impurity. Following surgery they see themselves as less of a woman and are afraid that their partner may go off them (Rider 1997). In another study it was found that those considering themselves to be healthy and fit (and therefore not harbouring any serious disease) did not understand the concept of screening (Hoare 1996).

The relevance of cultural epidemiology

Although the health beliefs in a population are likely to relate in some way to what people actually do in practice, it is essential to have a knowledge of how these beliefs are distributed in a population. Much of the health belief literature is predicated upon the rather naïve idea that if health beliefs can be elicited from a small sample of the population (qualitative studies typically deploy 20–40 participants or so) these beliefs will apply to the whole population. This is based upon a simplistic notion of culture as being homogenous and health beliefs being part of that culture. It is important to see how these beliefs are distributed within a population using epidemiological techniques. Only by doing this can health interventions be planned and implemented. It is not enough to use small scale qualitative studies to plan health interventions; these studies provide the basis for further quantitative studies. Both qualitative and quantitative studies are essential for health education and intervention programmes. For a good discussion of this approach in psychiatry and tropical medicine see Weiss (2001).

The metaphorization of cancer

Anthropologists describe how disease labels can be applied to society and similarly social labels (usually pejorative) are often applied to certain diseases. Cancer has occasioned a constellation of metaphorical systems. Even the name cancer itself is a metaphor deriving from the Latin word for crab denoting a swollen protuberance like the legs of a crab. In contemporary Western society cancer is fraught with fantasies of rot invading the body and animals that gnaw and destroy it (Herzlich and Pierret 1987: 56).
In the UK a number of metaphors are used for cancer relating to its severity and evasion of medical treatments. These include ‘unrestrained’, ‘uncontrollable’, ‘chaotic’ or ‘evil force’ – a disease which might afflict anyone at any time in any place. In the popular imagination cancer equals death (Sontag 1989). It is a disease which in modern Western societies is often viewed as being brought upon oneself through irresponsibility, bad diet, smoking or by the suppression of angry or negative thoughts (Lupton 2004).

The metaphors carry a range of symbolic associations and determine to some extent how sufferers perceive their own condition and how other people respond to them. Metaphors may be stigmatizing and might lead to avoidance of those with the condition. Peters-Golden (1982) has described how the stigma associated with breast cancer can result in other people avoiding the sick person possibly on account of the belief that the disease is in some way contagious. One study in Italy indicated that women themselves may see breast cancer as a ‘plague’, a malevolent force that has invaded them from the outside (Gordon and Paci 1997).

The dominant discourse surrounding cancer in modern society today is that of ‘hope’. This postulates that winning the ‘war’ against cancer is intimately linked to having a positive attitude to getting better. This discourse emphasizes ‘will’ and the idea that ‘if one has enough hope, one may will a change in the course of the disease in the body’ (Good et al. 1990: 62) hence underlining notions of individualism, fighting spirit and the power of thought in contemporary American society. These beliefs can lead to demoralization, depression and self blame when the cancer patient fails to be cured or the cancer returns. This discourse supports the current ethic of disclosure in the USA.

The militarization metaphor of ‘fighting’ is also prevalent. Erwin (1987) argues that the militarization metaphor for cancer leads to the expectation that patients will ‘fight’ the cancer. Cowardice, giving in, fear and denial are not considered socially acceptable ways of dealing with the disease. Optimism and positive coping are expected. Similar attitudes relate to physicians treating the cancer (Erwin 1987: 21): ‘For the medical doctor the long range goal is to determine which treatment protocols produce the best statistical curves – that is, in his opinion, the way to win the war. The war is his career. Fighting a single battle is the concern of the individual patient/soldier’.

**Concepts of the self, autonomy, agency and responsibility**

Cultural conceptualizations relating to the self and autonomy may be cross-culturally variable and this may have significant implications for the treatment of cancer in these groups. It cannot be assumed that the dualisms we take for granted in Western culture occur worldwide. Self–other and
mind/body dualisms may be specifically Western cultural constructs. Notions of the person and self vary across the world. One broad generalization is that in non-Western cultures notions of self and personhood are closely tied to belonging to a social group. The notion of the unique, bounded, rational, autonomous individual is a Western construct (see Morris 1994; Markus and Kitayama 1991 for a good discussion of cultural aspects of the self).

For instance, in Africa, Nobels (1991: 55) points out how:

Unlike Western philosophical systems, the African philosophical tradition does not place heavy emphasis on the individual – whatever happened to the individual happened to the corporate group, the tribe, and whatever happened to the tribe happened to the individual . . . a cardinal point to understand the traditional African’s view of himself, his self concept, is that he believes ‘I am, because we are; and because we are, therefore I am’.

In African American communities unity and kinship are valued. Self-preservation and individualism are not valued. This is significant in the planning and implementation of community based health programmes. Failure to include community members in cancer screening programmes’ design and their implementation and evaluation, interrupts collective unity and kinship (Jennings 1996).

There may be significant cross-cultural differences in the ways that individuals are held accountable for their illnesses. Especially in the Western world, ill health is increasingly blamed on not taking care of one’s diet, dress, hygiene, lifestyle, relationships, sexual behaviour, smoking and drinking habits and physical exercise. The extent to which people believe their health is determined by their own actions as opposed to luck, chance or external factors correlates with socio-economic variables (Pill and Stott 1982). The term ‘agency’ refers to intention or consciousness of action, sometimes with the implication of possible choices between different actions. The sense of personal control may be culturally variable. In India, for instance, patients’ feeling of well-being depends less on a sense of personal control than in the West (Saxena 1994). The family plays a significant role at each stage of diagnosis and management (Chaturverdi 1994). There is a similar state of affairs among certain ethnic minorities in the USA (Meyerowitz et al. 1998).

In Britain and the USA sick patients and their families make use of an explanatory framework which often includes a moral or quasi-moral judgement. The individual is held accountable for various disorders to different degrees. Diabetes, along with some cancers, brain haemorrhages and many common infectious diseases stand at the least blame end of the spectrum. The individual is generally not held to be responsible for developing these disorders. Sexually transmitted diseases, cirrhosis of the liver and lung
cancer are more strongly associated with a personal contribution towards the cause of the suffering (Crawford 1980). The allocation of ‘blame’ to individual sufferers of illness to some extent will determine their responses to this illness.

**Locus of control and fatalism**

Culture determines how people respond to misfortune. In groups who hold a fatalistic outlook on life, the belief may be held that the individual cannot necessarily exercise control over his or her health. This attitude, which sees health as being largely determined by forces outside the control of the individual and thus denies the relevance of individual behavioural change, is referred to as fatalism. As will be discussed below, fatalistic attitudes towards cancer are still prevalent in many parts of the world. Davison *et al.* (1992) point out how the Western approach to health education takes individual control as correct, whereas belief in other agencies requires rectification (usually education). Health promotion is seen as a struggle between a modern belief in lifestyle and an outdated belief in fatalism. However attempts to modify lifestyle to prevent disease onset in groups who hold fatalistic outlooks on life may not be well received. In such groups holding fatalistic ideologies, patients with cancer may ‘accept’ their imminent demise and refuse potentially life-saving treatment. Psychosocial responses including fear, underestimation, fatalism and pessimism have been identified as factors inhibiting Black American patients from participating in health promotion behaviour (Jennings 1996; Long 1993). Cultural groups differ significantly in the degree to which fatalism is part of their general worldview.

**Narrative in medical anthropology**

The study of language has close ties to the study of culture. This relationship was perhaps best illustrated by Claude Levi-Strauss’s work on structuralism (Levi-Strauss 1958) which applied linguistic theories to ‘explain’ cultural phenomena. In the past decade all areas of the humanities and social sciences have developed an increasing preoccupation with language, and an increasing recognition and understanding of the role of language in constituting and maintaining notions of reality. This reflects the ‘linguistic turn’ in the philosophy of science (Kvale 1992), characterized by a change in emphasis from a confrontation with nature to a focus on conversation, and from a correspondence with an objective reality to the negotiation of meaning. There has been a shift from psyche to text. Language is seen as possessing the power to create and organize our experiences.

Related to this is the contemporary emphasis on the pervasiveness of
stories in all human thought and action (Dein 2004b). Over the last decade, narrative has been a subject of increasing interest among social scientists. The term ‘narrative’ relates to the telling of some true or fictitious event, or connected sequence of events, in which the events are selected and arranged in a particular order (the plot). According to the narrative approach, we live in a ‘storied’ world, we make sense of things by telling stories to ourselves and others.

A number of social scientists have focused on narrative specifically within the realm of illness. Recording and analysing the narratives of patients and professionals can provide key insights into beliefs, attitudes, behaviours and barriers to change. Kleinman (1990) in his The Illness Narratives: Suffering, Healing and the Human Condition argues that doctors need to listen to the patient’s story about their illness in order to understand their illness experience. Good (1994: 133) posits that narrativization is a process through which the lifeworld of the sick patient, shattered by illness, is reconstituted. Similarly Skultans (1998: 232) argues for narrative resulting in a reconstruction of the self and identity for the sick person:

Everyday routines and relationships, hitherto taken for granted, are disrupted, and explanations can no longer be met. Sometimes these changes require a fundamental reconstruction of one’s sense of self and identity. Narrative is the means by which such changes can be brought about, since personally constructed stories about the self provide a space in which values can be reasserted and new roles described.

It is perhaps Frank (1997), a sociologist and himself a sufferer from cancer, in his book The Wounded Story Teller: Body, Illness and Ethics, who most persuasively writes about the principal plots of Western illness narratives: the restitution, the chaos, the quest and the testimonial narrative. He points out that in any illness, all four narrative types are told alternatively and repeatedly. Each narrative reflects strong cultural and personal preferences and is shaped by existing genres of storytelling in a society. The restitution narrative dominates stories of most people who have become recently ill and sometimes those who are chronically ill. By restitution he means narratives characterized by ‘yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again’. However bad things look, a happy ending is possible. Clinicians cannot entertain the chaos narrative (its plot imagines life never getting better) since it threatens the ‘triumph of modernity’ including the power of biomedicine. Frank writes (1997: 112) ‘The restitution narrative demands hegemony: it denies chaos and requires chaotic bodies to be depressed and thus fixable’.

Cancer destroys the ‘taken for grantedness’ of everyday life and results in fear and uncertainty. It results in ‘suffering’, a term commonly deployed by those with the illness and one that is difficult to define. Cassell (1982: 639) refers to suffering as relating to a number of interconnected threats and
losses: losses to personhood; threats to the identity; threats to the person’s future; threats to self-image; a perceived lack of options for coping; a sense of personal loss and a lack of a basis for hope. He goes on to state how

the test of medicine should be its adequacy in the face of suffering . . . modern medicine fails that test. In fact the central assumptions on which twentieth Century medicine is founded provide no basis for an understanding of suffering. For pain, difficulty in breathing, or other difficulties of the body, superbly yes, for suffering no.

(Cassell 1982: 639)

In a similar way the Irish palliative care physician Michael Kearney (1997) states how the medical model is aptly able to deal with the physical aspects of pain but is unable to deal with the nature of suffering entailing threatened loss to the integrity of the person.

This loss of a sense of bodily integrity is well illustrated in a study by Chattoo et al. (2002) which used in-depth qualitative interviews to elicit the narratives of South Asian (Indian, Pakistani and Bangladeshi origin) and White people with advanced cancer and their carers in the UK. They used a biographical approach and compared narratives across families and ethnic groups to understand the salience of ethnicity in relation to gender, age and socio-economic position in shaping the illness and caring experience of the research participants. This study illustrates the centrality of the notion of discontinuity and fractured self in understanding the impact of cancer on different aspects of identity and points to the difficulty in the re-negotiation of identity in relatively young communities where the experience of cancer is far less common than in the White population.

There is a growing awareness of the role that narratives play in helping cancer patients cope with their illness. Narratives can be deployed to objectify and distance oneself from problems, to gain understanding, establish meaning, develop greater self knowledge and decrease emotional distress. In relation to this, Carlick and Biley (2004) argue that there is a need for health professionals to incorporate the use of narratives into their practices. To date, however, the cross-cultural study of cancer narratives is in the embryonic stage. In terms of cancer, cultures may differ in the ways that they recount their ‘cancer narratives’. These may have significant implications for communication and treatment. Although little studied, this is a fruitful area for further research. Potential areas might include the ways that different groups structure their narratives and the influence of ‘cultural narratives’ on individual response to cancer and its healing. Beyond this there is some anecdotal ‘evidence’ that the recitation of narratives might themselves be ‘healing’ for cancer patients.
The expression of emotion

Cultural factors determine the ways in which symptoms are expressed and the psychological response to cancer. Although far from simple, anthropological experience in non-Western cultures suggests that the Cartesian split between mind and body which we find in Western cultures is not present in other parts of the world. In Western society the duality of mind and body is hierarchical, with intellect over emotions and the soma. Somatic distress is seen as secondary communication of primary psychological distress. In contrast, in other cultures, such as Buddhist and Hindu traditions, feelings and intuitions have a higher value than words and the emotional response to cancer may be predominantly somatic – that is expressed through bodily symptoms. Somatic presentation of complaints is not related to a lack of vocabulary or sophistication of psychological processing as much as to a conceptual difference in the primacy of the body as the appropriate vehicle of communication for both physical and emotional distress (Kagawa-Singer et al. 1997).

Somatization, the expression of psychological distress through physical symptoms, is common in non-European cultures (Jablensky et al. 1981; Marsella et al. 1985; Ramirez et al. 1991). The phenomenon of somatization may be frequently found in certain ethnic minority populations in the West including Indians, Pakistanis and Bangladeshis (Bal 1987; Mumford 1993). Some cultures may have difficulty using the word depression. For instance, Muslims may not use the word depression since feeling depressed demonstrates a lack of respect for Allah.

Understanding these idioms of distress has important implications for health professionals working with cancer patients. Failure to understand the mode of emotional expression might result in an overemphasis on physical symptoms and the neglect of underlying psychological distress.

Summary

The above discussion illustrates the variety of ways in which cultural factors may influence understandings of and attitudes towards cancer and the response to it. A problem for medical anthropologists is how to incorporate these anthropological themes into practice and to develop a clinically applied anthropology. This is discussed in following chapters. These themes will recur throughout the book and have significant implications for those working with cancer patients from various cultural groups. In particular, the book will adopt a critical stance towards concepts such as culture and ethnicity. Working with ethnic minority groups involves more than just addressing the ‘problem of culture’; it must extend to an examination of the
wider social constraints – including racism and discrimination – in which these cultural beliefs are embedded.

**Further reading**


