

Chapter 3

Theoretical Underpinning of the Study

It is important to emphasize that the relationship between man [sic], the producer, and the social world his product, is and remains a dialectic one. That is, man (not, of course, in isolation but in his collectivities) and his social world interact with each other. The product acts back on the producer (Berger & Luckmann 1971, p. 78).

Introduction

The previous chapter reviewed the literature on anticipatory grief and demonstrated that previous empirical studies have been based on the positivist understanding of social reality. This paradigm assumes the existence of an apprehensible reality driven by immutable, natural laws and mechanisms. An implicit positivist assumption is that there is a direct, uncorrupted link between the existence of a physical reality and the concepts researchers use to explain it. Previous empirical studies on anticipatory grief have assumed that the phenomenon is 'real'; it is an event that is intrinsic to the process of confronting an impending loss and exists independently of the observer (Rando 1986a, 1988). A further assumption is the belief that, theoretically, it is possible to develop a research project to eliminate all interpretive bias and understand things 'as they really are'. All that is required is the development of a research project that takes into account all the variables associated with the phenomenon being investigated. However, the inability of prior research to produce consistent and conclusive information concerning the effects of this 'syndrome' leads to questioning what actually 'exists' in regard to anticipatory grief.

Social constructionism is another, equally valid, way of conceptualising the nature of phenomena and how they can be studied. The above quotation from Berger and Luckmann (1971) highlights a major implication of social constructionism: Reality is constructed through human action and does not exist independently of it. This does not mean that the world exists only in the minds of human beings but rather, the world as a meaningful reality is constructed through human interpretive activity (Mishler 1981). However, human beings not only construct the world in which they live but also construct images of themselves and

use those constructions of the world and their self-images during interaction with others and society in general.

The purpose of this chapter is to present the theoretical underpinning of the current study. It presents the theoretical assumptions of symbolic interactionism relevant to the study of the experience of living with a life-threatening illness. Consequently, it begins with a brief introduction to the individual in society before introducing the main concepts of symbolic interactionism. The importance of language and discursive processes and practices in the ordering of perceptions, the determining of subjectivity, the construction of social interaction, and the making of diverse social and physical worlds meaningful for social actors is also presented. The concept of discourse, as a way of coherently describing and categorising the physical and social worlds, is introduced. The distinction between common sense and professional discourse is made and related to the current research problem. The power of discourses to persuade audiences to accept a particular version of reality over another is discussed. The chapter also introduces the concept of health as it is used in the construction of self and the unhealthy 'other' and the impact it has on interrupting social relations. The chapter concludes with a brief discussion of how individuals symbolically designate elements of the medical discourse and then act toward those objects.

The Individual and Society

Max Weber incorporated the problem of '*Verstehen*' in his approach to sociological inquiry and exposed us to the notion that individuals can understand, or attempt to understand their own intentions through introspection. Individuals also interpret the motives of other individuals' actions in terms of their professed or ascribed intentions. Whereas Karl Marx ascribed meanings to the process of social interactions, that is, the objective meanings of social interaction irrespective of the participating individual's awareness, Weber recognised that the meaningful and symbolic interactions among actual people were the reality behind the macro structures of society (Geth & Wright Mills 1970). In other words, reality was composed of the interactions between individuals rather than the social structure of classes, the state, institutions, and nations. For Weber the real world consisted of individuals who not only interpret and give meaning to the reality around them but also act in terms of these meanings (Coser 1977; Turner 1978).

This interactionist approach was taken up by later philosophers, psychologists and sociologists such as William James (1890), Charles Horton Cooley (1964), John Dewey (1886, 1922) and George Herbert Mead (1938, 1964). James, perhaps the first social scientist to develop a clear concept of self (Turner 1978), believed that humans have the capacity to view themselves as objects. James (1890) suggested that just as individuals could denote other people and aspects of the world about them symbolically, develop attitudes and feelings towards these objects, and construct typical responses towards objects, they could also denote themselves symbolically, develop self-feelings and attitudes, and construct responses toward themselves. These capacities James called the self. Furthermore, he recognised the importance of this self in shaping the way individuals respond to the world.

Cooley (1964) refined James' concept of self in two ways. Firstly, he saw self as the process by which people see themselves as objects, along with other objects in their social environment. Secondly, Cooley recognised that self emerges out of communication with others. More precisely, through social interaction, individuals interpret each other's gestures and are thus able to see themselves from an alternative viewpoint. He proposed the concept of 'the looking-glass self' to indicate the process of reacting to ourselves by anticipating how others will react to us (Epstein 1980).

Symbolic Interactionism

Drawing on the work of Mead, Blumer (1969) claimed that symbolic interactionism is based on three premises. Firstly, human beings act toward objects in their environment on the basis of the meanings those objects have for them. Secondly, these meanings are acquired from social interaction between and among individuals. Thirdly, these meanings are established and modified through an interpretive process. To fully appreciate the application of symbolic interactionism to clarifying the issues associated with living with a life-threatening illness, and in particular the concept of anticipatory grief, it is important to identify the main concepts and terms such as 'reality', 'symbols', 'objects', 'social acts', 'self as object', 'self as process', 'definition of the situation', 'roles' and 'perspectives'.

The nature of reality

Symbolic interactionists operate from the assumption that a number of realities exist, namely an objective reality, a social reality and an individual or subjective reality (Charon 1992). A physical objective reality exists independently of social definitions applied to it. For example, 'cancer' exists as a group of cells within the body that grows excessively or fail to die appropriately and, similarly, 'HIV' exists as small particles composed of complex molecules of protein and nucleic acid. This objective reality is interpreted and constantly renegotiated in the course of social activity. This social reality is dependent upon the socio-historical settings in which they occur (Lupton 1994a). For example, Sontag (1991) examines how, historically, societies have ascribed a social meaning to cancer, and later HIV/AIDS, through the use of metaphors. For example, cancer is not simply perceived as a disease but also as a metaphor for evil, a 'demonic pregnancy', an invader, a disease of industrial society, the wages of repression of feelings, and a shameful disease.

In addition to this social reality an individual or subjective reality exists because each individual sees the world uniquely (Charon 1992). The human body responds biologically to the objectively existing phenomena. However, individuals not only respond physically to this objective reality but also to the social definitions that have been developed through interaction with others and applied to the objective reality. Individuals interpret the effects of the physical response and decide on a line of action. For example, the growth of cancer cells may cause pain which the individual interprets (e.g., Is it minor or severe pain? Can I tolerate this pain? Is this the same type of pain that occurred previously?). The individual then defines the pain accordingly (e.g., It is nothing to worry about. This pain is serious.) before deciding what action to take (e.g., I'll do nothing. I'll wait another week. I'll have it checked out by the doctor).

The importance of socially defined reality is obvious when considering the innumerable physical objects that an individual encounters in daily living and must identify, catalogue, interpret and apply meaning. To a great extent this is done by the society in which the individual lives and individuals identify and classify their world according to what they learn from others during interaction.

Social objects

Although objects may exist in a physical form they become social objects for human beings when they are identified, catalogued, interpreted and given meaning through social interaction. That is, social objects are defined according to their use for people in each situation (Charon 1992) and, simultaneously, as a goal of an individual's action (Hewitt 1997). The meaning ascribed to each physical object is not intrinsic to the object but arises from how the individual is initially prepared to act toward it (Blumer 1969). For example, HIV constitutes a multitude of social objects: for the biomedical and social scientist it is a disease for scientific study; for the medical practitioner it is a fatal disease whose symptoms require palliative intervention; for the devout Christian it is divine justice for sinful behaviour; for some members of the community it is a disease of death; for others it is deviance, an enemy, a mystery or homosexual.

Charon (1992) defines a social object as any object in a situation that an actor uses in that situation and where that use has arisen socially. In a particular situation individuals act toward socially defined objects that are of use to them. As this action unfolds individuals may change their use of objects, notice new objects or ignore initially used objects. Individuals shape their world through interaction. Instead of objects remaining simply as 'physical things' they are defined and used by individuals to achieve their goals in any given situation. Furthermore, they are changed by individuals according to their needs. During the experience of living with a life-threatening illness individuals encounter a multitude of new objects (e.g., pain, health care professionals, therapeutic drugs, other patients). They also encounter new situations such as consulting specialist medical practitioners, admission to hospital undergoing surgery, chemotherapy or radiotherapy, surgical disfigurement, social and emotional rejection by others. These new objects and situations must be interpreted, given meaning, acted toward and discarded or meaning changed. For example, an individual with cancer may interpret forthcoming surgery as 'life saving' and then post operatively, when the disfiguring effects of the surgery are acknowledged, may change their interpretation of the surgery to that of 'mutilation'.

An important class of objects is the varying types of expectation structures (e.g., norms and values) that may exist to guide interaction. It is toward these objects that individuals have a

disposition to act. Consequently, to understand the potentials for action among groups of people, for example those individuals living with a life-threatening illness, it is necessary to understand the world of objects that they have symbolically designated.

Mead (1964) argues that social objects are objectively real features of the social environment and are experienced as universal and real when individuals share a common perspective. For nonphysical social objects, such as the self, roles, marriage or emotions, validation rests with social interaction. Furthermore, it is the sharing of perspectives that confers objectivity to all social objects (Callero 1986). As will be discussed in the section on discourse, this has important ramifications for the current study.

Symbols

The concept of the symbol is the most important conceptual block on which symbolic interactionists base their analysis of human conduct (Hewitt 1997). Symbols are a class of social objects that are used not only to represent whatever individuals agree that they shall represent but also to communicate between individuals and within the individual (Charon 1992). Symbols are meaningful, significant, arbitrarily associated with what they represent and used purposively to convey meaning that is believed to make sense to others. That is, the user understands what the symbol represents, as does the person who receives it, its meaning is not found in nature but is created and assigned by people and used to convey meaning to another person.

Some confusion can arise from the observer's standpoint in identifying symbols. An observer may interpret another individual's actions even when the individual did not intend to communicate. For example, a facial grimace, which is not a symbol for the individual, may be interpreted by an observer as a frown. The observer may also interpret the 'frown' as the individual communicating displeasure with the observer. Although the unintended body language is not a symbol for the individual, for the observer it is interpreted as a clue as to what the individual is thinking in the situation. The act of making a facial grimace, like all observed acts, is actually a social object to the observer. They are not symbols to the individual because the individual is not using them for representation and communication. The critical factor for symbols is that something has meaning to the individual who gives it

off. As the individual communicates to others, he or she understands the action. Charon (1992, pp. 45-46) suggests that:

Whatever is given off - symbols or unintended forms of communication - is noticed and used by others (and is therefore a social object) or goes unnoticed and unused. It is this remarkable ability to manipulate representations intentionally, for the purpose of communication, that gets at the nature of the human being.

Social acts

Individuals organise their conduct in relation to objects in their environment through what symbolic interactionists refer to as social acts. Hewitt (1997, p. 43) defines an act as "... a functional unit of conduct with an identifiable beginning and end that is related to the organism's purposes and that is orientated toward one or more objects". Furthermore it is the elementary unit of conduct that represents the smallest unit that can be abstracted from the stream of human behaviour. This act is a functional unit of conduct in that it has a relationship to the individual's purposes. It has a coherent, identifiable relationship to what the individual must do to stay alive and healthy, to accomplish other goals, or to satisfy the expectations of other people. For example, 'consulting the doctor' is a discrete unit of behaviour that has the attributes of a social act; it has a more or less definite beginning and has a definite end. It begins with the patient walking into the doctor's waiting room and ends when the receptionist has been notified of the patient's arrival, the patient has entered the doctor's surgery, the patient and doctor have completed their interaction, the patient leaves the doctor's surgery, the patient makes another appointment with the receptionist or receives/pays the account and the patient leaving the doctor's waiting room.

To engage in social interaction and thus complete the social object of social interaction people must be able to interpret one another's acts (Hewitt 1997). Furthermore, those engaged in interaction must be able to interpret or assign meaning to the acts of each other in such a way as to enable them to act appropriately. Interpretation of another's acts focuses on their intent; individuals ask themselves what others intended when they made a statement. For the individual, meaning consists of asking the question 'what am I going to do, what will others do in return, and what will I do in response?' Hewitt (1997, p. 47) suggests that meaning is triadic:

When an individual acts (by making a statement or command, shaking a fist or turning away, or even by means of a facial expression), she indicates to the

other what she plans to do, what the other is expected to do in return, and what social object is being created by them.

Since much of daily living is routine a great deal of what individuals do can be explained in terms of habit. These habitual forms of conduct involve basic skills that are so ingrained and repetitively experienced that the individual rarely has to think about them unless these every day taken for granted assumptions are called into question. However, it is the problematic situation or event that makes it necessary for individuals to orient themselves self-consciously to objects and try to interpret one another's acts. Under these different circumstances, when something interferes with the progress of an act toward its usual object, individuals become more keenly aware of the object itself and of the most appropriate ways of designating and responding to others' acts. It is at these times that individuals' capacity to designate and interpret is crucial to the success of the individual's action (Hewitt 1997). Diagnosis of, and living with, a life-threatening illness can be a complex amalgam of such problematic situations.

The self

The term self is used in many different ways in everyday speech. However, for symbolic interactionists the concept of self is used to designate both the object that is created during interaction with others and the process through which this object is created (Charon 1992; Hewitt 1997). The importance of self as both process and object lies in the fact that self is crucial to the way humans regulate what they do.

Self as object

The self as a social object originates through interaction with parents and other individuals during childhood and undergoes constant change throughout life as the individual interacts with others in various situations (Charon 1992). Through this interaction with others the individual comes to see self as a separate object that can be named, imagined, visualised, talked about, and acted toward. Perceiving the self as an object means that the individual can also act toward this self as object with the same range of motives and emotions that shape actions toward other objects (Charon 1992; Hewitt 1997). That is, the individual can like or dislike this self, feel pride or shame in a real or imagined situation.

The self not only arises in social interaction with others, but, like all social objects, is defined and redefined in this interaction. How individuals perceive themselves, how they

define themselves, and how they judge themselves is dependent on the social definitions encountered throughout their individual life (Charon 1992). The implication of this view for individuals living with a life-threatening illness is that how individuals perceive and define themselves throughout the illness experience is dependent on the social definitions applied to this situation. (This issue is discussed in greater detail below.)

Self as process

The distinction between self as object and self as process is clarified by using the Meadian terms 'I' and 'Me'. The term 'I' is sometimes used to indicate the individual as subject that responds to a social situation. That is, the individual's 'I' is person as actor and is that aspect of the individual that gives propulsion to acts (Charon 1992). However, it is more easily understood as that part of the individual that is spontaneous, impulsive, unsocialised by society, not used by the individual, but instead causes the individual to do things not thought of (Charon 1992; Hewitt 1997). The 'I' is that part of the individual that does not arise from interaction with others. Individuals' awareness of their initial response to a stimulus signals the beginning of the 'Me' phase of self. For example, when the doctor delivers a diagnosis of cancer individuals may spontaneously begin to get upset or cry, but check themselves and continue to ask questions of the doctor. In this situation the immediate response of crying is the response of the individual's 'I'. In checking their response the individual has responded to the imagined attitudes and values of the other (the doctor or a preconception of self) to the spontaneous response of crying and selects an alternative response. In taking the point of view of the doctor (or the preconceived self-image) the patient becomes the 'Me'

The importance of self

The self is one of the most important symbolically designated objects. The significance of the self as object is that in a sense the individual has an additional person to act toward in any situation. Individuals can act toward the self by engaging in a conversation with themselves (e.g., the everyday experience of 'talking to oneself') or internalising this conversation in what is called 'thinking'. In effect, in conceiving of thinking as internalised conversation, what is called 'mind' or 'consciousness' is actually the incorporation of social process within the organism. Consequently, people have minds because they are able to act toward themselves, talk to themselves, and consider their own symbolic representation of themselves as they act in any situation (Hewitt 1997). Furthermore,

without this self-communication human beings would not be able to communicate symbolically with others. Charon (1992, p. 77) suggests that:

... it is only because the human can simultaneously give off meaning to other people and understand (through communication with self) what he or she communicates, that effective symbolic communication can take place.... Only humans can self-consciously and purposively represent to themselves that which they wish to represent to others.

In communicating to the self individuals analyse and define the situations in which they act. That is, individuals indicate to the self information about all objects in any given situation. This includes information about the self as object. This selfhood enables individuals to examine situations and objects within situations and how they affect them. Furthermore, it enables individuals to determine what type of action might be taken by imaginatively testing the effects of proposed action first on the object individuals seem to know best, the self.

Individuals have multiple ideas about self which affect action taken. They also have self-control and can inhibit acts, consider several alternative options, select one considered appropriate to the situation and then act accordingly. This perception of self is often referred to as the individual's 'self-image'. It is the 'picture' individuals have of themselves and consists of individuals' thoughts and feelings with reference to themselves (Charon 1992). Although this self-image is stable across situations and over time it is also a shifting, adjustive process of self-presentation in social interaction (Rosenberg 1981). This self can represent the transitory images that an individual derives from interpreting the gestures of others in the current situation. Furthermore, it can represent the more enduring conceptions individuals have of themselves as an object that they bring to, and interject into, any interaction. Examples of these latter self-images, that may be interjected into an interaction during the experience of living with a life-threatening illness include being 'a spouse/partner', 'a parent', 'a sibling', 'an adult child', 'a healthy person', 'gay', 'a patient', 'a doctor', 'an ex-nurse', 'a health care professional (HCP)', 'a member of the general community', and 'unlucky'.

Definition of situation

Human conduct occurs in specific, concrete and usually well known situations that present individuals with acts and objects in familiar configurations. The term for this configuration

is the 'definition of the situation' and is formally defined as "... an organization of perception in which people assemble objects, meanings, and others, and act toward them in a coherent, organized way" (Hewitt 1997, p. 56). The significance of this concept is that where a situation is familiar and its configuration of meaning is known, individuals organise their own conduct and their expectations of others in relation to its definition. For example, patients and health care professionals in a hospital usually act on the basis of a familiar definition of a situation. Both groups know that the situation includes the other and both will act toward such objects as medical tests, treatment interventions, emotions, taking medical histories and asking personal questions.

The definition of a situation not only allows individuals to anticipate or understand the actions of others but also provides an important basis for individuals' capacity to see themselves. A definition of the situation allows individuals to see themselves as part of it. Because such definitions of situations provide individuals with information about what is going on and who is making what happen, they are able to see who they are and what they are supposed to be doing (Hewitt 1997). The self as object that arises as individuals grasp the meaning and direction of their act is always a situated self; a specific self-image arises in a specific situation.

Each person defines a situation in terms of the relevant cluster of objects and of the dispositions to act that these imply. This definition of the situation serves as a general frame of reference or perspective, within which the consequences of particular lines of conduct are assessed (Turner 1978). For example, health care professionals integrate the theory developed from the empirical studies reviewed in Chapter One in defining the situation of individuals living with a life-threatening illness. The concept of anticipatory grief is a central structure in the frame of reference used by health care professionals in their assessment of the line of conduct of individuals who are confronted with the expectation that they will encounter a significant loss. Health care professionals' interpretation of anticipatory grief, its nature and effects is also integral in influencing their subsequent interaction with such individuals.

Roles

Within structuralism role is generally conceptualised as a set of normative expectations, rights, duties and obligations attached to positions or statuses in the social structure (Callero 1986; Hewitt 1997; Noyes & Clancy 1977). That is, a position or status in society obligates the individual to undertake certain duties. For example, the sick role requires patients to get well and obligates them to obtain competent help in an effort to regain their health. Furthermore, patients are expected to cooperate with prescribed treatment. At the same time, patients ascribed the sick role have a right to be exempt from the responsibilities of their usual social roles and a right to be cared for (Noyes & Clancy 1977). These normative requirements provide guidance for individuals as they try to construct their conduct. The norms that define the role provide individuals with a script for any situation in which they are called upon to 'play' the role

However, symbolic interactionism recognises that a role is both a social object and a perspective from which individual perception and action originate (Callero 1986). Recognising roles are social objects establishes two important defining characteristics of a role: roles are social constructions dependent for their existence on social interaction, and roles are stable and objectively real features of social structure which are recognised and used by all members of the community (Callero 1986). The first characteristic is generally considered to be an important contribution of Mead's social behaviourism: social objects are considered to emerge in the course of interaction and exist only in relation to others. Consequently, as a social object, a role must be premised on the action of others toward it. The second characteristic is less well recognised but still important to understanding the implications of social role as social object: social objects are objectively real features of the social environment and are experienced as universal and real when individuals share a common perspective (Mead 1964). For example, the roles of patient, doctor and nurse are generally recognised and used by all members of society. It emerges in the course of interaction between individuals, who are unwell in some way, seeking the expertise or advice of other individuals, who are considered to possess special knowledge that restores health (e.g., doctors, nurses).

Callero (1986) argues that roles, as social objects, represent patterns of social action which are identified, classified and shared by all members of a particular community. Furthermore, they belong to the social environment and can not be subjectively held as constructions. As socially defined objects, roles are relative to a social community and must be taken into account during social interaction where they may even be the object of the social act. However, they are not arbitrary classifications but particular roles exist because they have demonstrated success as facilitators of social interaction. Roles distinguish themselves from other social objects in that they are also used to define the self. In defining the self, roles also function as a perspective: they serve as a basis for perception, as a basis for organising and classifying the world and, ultimately, as a basis for action. Roles are not only contingent on perspective for their definition but also they are the source of perspective.

Mead (1964) suggests that all living organisms actively engage their environment, selecting stimuli with which to interact, as opposed to passively responding, and, therefore, interact within perspectives. Hence, a perspective represents a particular way of structuring the world. Individuals are born into a pre-established community perspective which allows for a common way of structuring the world and leads to common attitudes and common objects that exist for all members of the community (Callero 1986). For example, the common sense discourse of cancer, as a community frame of reference that allows for a common way of structuring the world of cancer, predates the individual (a situation that does not yet exist in respect to HIV/AIDS). Callero (1986, p. 347) argues that "... it is from this community perspective that individual perspectives emerge and allow for individualistic responses. In fact, the individual must be aware of other and learn to take the perspective of other before a self can develop." Callero also stresses that the community frame of reference is not a transcendent perspective that somehow exists independently of the frame of reference of individuals. Neither is it built up of individual perspectives (Mead 1938). The community frame of reference represents an organisation of individual perspectives. Individual frames of reference are coordinated and ordered by social actors who have the ability to consider others' perspectives within the social act. As a perspective, a role represents both an organised community approach to structuring certain aspects of the social world and a more unique individual approach (Callero 1986).

The unique character of individual perspectives and responses is realised in at least three ways:

First, each actor represents a unique part of the social structure and as a result reflects and combines community perspectives in an uncommon way ... Actors are defined by multiple roles and thus possess multiple perspectives in unique combinations. Second, even though roles are shared social objects, perspective allows an actor to use roles in unique ways....Third, perspectives operate through imagery at the individual level. (Callero 1986, p. 348)

This concept of roles as social object and as perspective has important implications for the current study. Both life-threatening cancer and HIV/AIDS are social objects with which members of the community interact. The role of cancer patient has emerged, and continues to do so, in the course of interaction primarily between the individual with cancer and a restricted group of individuals within the community, namely other individuals who are deemed to possess skills and expertise aimed at 'curing' the cancer and restoring the patient to a healthy status (i.e., members of the medical community). However, this role is also recognised and used by all members of the non-medical community. For example, individuals who are not diagnosed with cancer also recognised and use the role cancer patient during social interaction with individuals diagnosed with cancer. Thus individuals diagnosed with cancer have an established social object with which they interact. This role of cancer patient represents patterns of social action which are identified, classified, shared and recognised by all members of the community. This cancer patient role facilitates social interaction between the individual with cancer and members of the medical community and community members who do not have a diagnosis of cancer. As a perspective the role of cancer patient provides individuals with a basis for perception of their experiences, a basis for organising and classifying the world and as a basis for action.

However, the same situation does not exist in regard to HIV/AIDS. The role of 'HIV/AIDS patient' is not as clearly defined. Gay political and community-based groups have been influential in defining, and combatting the disease as well as educating the community (Altman 1986, 1992b; Gilder 1989; Padgug 1987). Although individuals infected with the virus are medically classified as having a disease, and, therefore, fulfilling part of the requirements for the definition of 'patient' as a social object, not all members of the community agree on the patterns of social action identified and classified as constituting that role. For example, although members of the medical profession might identify and

classify certain patterns of social action as meeting the requirements of the patient role, infected individuals and HIV/AIDS activists may not agree (Altman 1986; Padgug 1987). The fact that individuals infected with HIV remain asymptomatic for varying periods of time means that the patterns of social action of these people in relation to the infection are not always the same for infected individuals who have developed opportunistic infections and are interacting with the medical community. Consequently, the patterns of social action of both groups of individuals, in interaction with non-infected members of the community, have been identified, classified and shared by all members of the community, not as 'AIDS patient', 'HIV patient' or 'HIV/AIDS patient' but rather as a person living with HIV/AIDS (PLWH/A). Therefore, as a perspective, the role of PLWH/A functions as a basis for perception, a basis for organising and classifying the world, and as a basis for action (Altman 1986; Siegel & Krauss 1991).

There are two significant differences between the roles of cancer patient and PLWH/A. Firstly, the purpose and orientation of each role. The role of cancer patient emerged in the course of interaction between individuals diagnosed with cancer and members of the medical community. Hence, its interaction is medically orientated. Alternatively, the role of PLWH/A emerged in the course of interaction between individuals diagnosed as infected with HIV and members of the broader community and hence has a focus on living with an incurable and fatal, infectious disease. Consequently, each role owes its existence to the fact that it has demonstrated success as a facilitator of social action between two different groups; primarily the medical community in the case of the cancer patient role, and members of the broader community for the role of PLWH/A.

Secondly, the role of cancer patient has been long established and had the opportunity to develop over a considerable length of time. However, the role of PLWH/A has only recently emerged (during the early 1980s) and developed over a relatively limited period. The significance of this difference in temporal development is that the role of cancer patient has had sufficient time for a greater understanding of it as a social object and perspective to develop within the broader community. As a consequence, the role of cancer patient is broadly understood and accepted within the community. On the other hand, the role of PLWH/A is still rapidly evolving and not well understood by members of the general community.

In relation to these theses, the critical issue is whether these differences in the social roles of cancer patient and PLWH/A, as social objects and perspectives, influence the illness experiences associated with each disease, in particular, interaction with their imagined futures.

Role taking

Role taking is the process of taking the perspective of the other or seeing the world from the perspective of other individuals or groups and taking that perspective into consideration during interaction (Charon 1992). That is, the individual imaginatively occupies the role of another, examines the self and situation from that vantage point and then takes appropriate action. Role taking always involves cognitively understanding the perspective of the other whose role is taken. Sometimes this process involves identification (Hewitt 1997). For example, in deciding to convey 'bad news' to a patient medical staff may imagine themselves in the patient role and their own reaction to such news. This symbolic interaction with the self then influences the way the information is transmitted.

Deciding to act

Selecting a particular line of behaviour in any interaction involves a complex symbolic process in which the individual typically makes a number of evaluations. These include evaluating (a) the demands of others immediately present (e.g., in the life-threatening illness experience it may be doctors, nurses, partners, patients, friends, members of the general community), (b) the self-images individuals develop through role taking, not only with those in the current interaction but also with others not actually present (e.g., self-images developed during interaction with family of origin), (c) the normative expectations they perceive exist in the situation (e.g., community norms and values), and (d) the disposition to act toward any other objects the individual may interpolate symbolically into the interaction (e.g., the specific disease, social representations of the disease, pain, treatment, the process of dying, and death) (Charon 1992). However, once emitted, behaviour does not necessarily remain static. Redefinition of the situation and general frame of reference may occur in response to the individual's interpretation of others' reactions and as new objects are injected into, and old ones discarded from, the situation. For example, in the euthanasia debate a person may have self-images as an 'anti-euthanasia

campaigner' and a 'practicing Christian'. As pain is one of the objects relevant to this debate the individual may, in the absence of a personal experience of severe pain, symbolically designate such pain as 'bearable' and/or 'a test from God'.

Furthermore, in terms of the cluster of these and other relevant objects, the individual may define a frame of reference that may centre on all forms of life being sacrosanct and current pain management regimes being adequate for any pain situation. However, when this individual is confronted with the actual experience of disease causing severe, unrelenting pain, new objects may be interjected into the situation (e.g., the experience of the disease, the unrelenting and debilitating nature of the pain, the absence of adequate pain relief, and absence of an acceptable quality of life). In this new situation this same individual, as a patient, may interact with other people (e.g., family, friends, HCPs), and interpret their actions as signifying that there is no hope of relieving the pain or achieving an acceptable quality of life. Given this new situation the individual may reconceptualise the self as not able to withstand pain, redefine the situation as 'unbearable' or 'unacceptable' and become a euthanasia supporter or a supporter of individual freedom of choice regarding euthanasia.

Language and development of meaning

Language is a special kind of symbol. More than any other symbol, it can be produced at will and can represent a reality that other symbols can not (Charon 1992). Interaction is in the form of communication, broadly understood, and is symbolic because humans communicate via languages and symbols. Furthermore, communication creates significant symbols (Schwandt 1994). Language and discursive processes and practices are integral in the ordering of perceptions, the determination of subjectivity, the construction of social interaction, and the making of diverse social worlds meaningful for social actors (Lupton 1994b; Potter & Wetherell 1987). In particular, language is central to the meaning of illness; to the ways people learn about and understand a disease or illness; to the types of experiences they have; and, to the moral judgements made about the causes of illness (Lupton 1994b). Illness is not limited to a physical experience. It is also experienced through the symbols of language. In relation to disease and illness, language is used:

... in the attempt to convey the pain or discomfort an ill person feels; words direct the relationship between doctor or nurse and patient; words nominate which kinds of people are considered to be 'at risk' of developing an illness and how they should be treated. (Lupton 1994b, p. 5)

However, language, as a collection of symbols governed by certain rules and used to convey messages between individuals, can be open to misinterpretation (Adler & Rodman 1991). Although words constitute the most symbols in spoken and written language, their selection, or absence, is critical in the meaning of the spoken or written message. Word selection positions the communicator in relation to specific issues, ideas and values (Lupton 1994b). For example, choosing the word 'victims', when referring to individuals living with HIV/AIDS, represents such people as passive, disempowered patients in a limbo existence while living out their 'sentence of death'. Similarly, when used to describe an individual living with cancer, the term 'sufferer' denotes powerlessness and the inevitability of a prolonged and painful decline to death. At the same time it connotes personification of the disease and its purposive selection of whom it will 'invade'.

The absence of adequate verbal symbols within the English language to convey bodily feelings is eloquently described by Virginia Woolf in her 1930 essay *On being ill*:

English, which can express the thoughts of Hamlet and the tragedy of Lear, has no words for the shiver and headache. The merest schoolgirl, when she falls in love, has Shakespeare or Keats to speak her mind for her; but let a sufferer try to describe a pain in his [sic] head to a doctor and language at once runs dry. There is nothing ready made for him. He is forced to coin words for himself, and, taking his pain in one hand, and a lump of pure sound in the other (as perhaps the people of Babel did in the beginning), so as to crush them together that a brand new word in the end drops out. (reprinted in Lupton (1994a, p. 55))

To compensate for this lack of suitable verbal symbols, particularly in relation to a novel experience, the use of metaphor has become common in all areas of verbal communication. When a novel experience is encountered for which no existing classification or category of understanding is available, the event remains unclassified and unassimilated. Meaning is only acquired through the structural coupling between aspects of the new experience and aspects of preexisting constructions (Neimeyer & Neimeyer 1993). Sarbin (1986) suggests that "... recognition of partial similarity on some dimension or construct provides the basis for analogy, and if linguistic translation is necessary, the partial similarity is expressed as metaphor. The novel occurrence is named with the metaphor".

It is not unexpected, therefore, that metaphors, analogies and other symbolism are frequently used to conceptualise, and articulate to others, the experience of disease and illness (Kleinman 1988; Lupton 1994a). As an epistemological device, the metaphor serves to conceptualise the world, define notions of reality and construct subjectivity (Clatts & Mutchler 1989; Lakoff & Johnson 1981). In comparing two non-associated entities a metaphor focuses on the ways in which each resembles the other. Consequently, the metaphor shapes perception, identity and experience, extending the original association by evoking multiple meanings (Clatts & Mutchler 1989). Importantly, the development of metaphorical associations is reliant upon pre-established knowledge and belief systems to establish meaning and extend these meanings in other directions (Lupton 1994a). For example, the military metaphor is extremely common in modern medicine, particularly in relation to infectious or life-threatening diseases such as HIV and cancer. Its effectiveness in conceptualising and articulating the experience of disease and illness relies on general knowledge of the language of warfare being held by both parties in the communication.

Metaphorical representations are not politically neutral. As a strategy used to persuade the acceptance of one meaning of reality over another, they are commonly used in ideological struggles around a contested site of meaning. In this situation, metaphor works to 'naturalise' the social, turning the problematic into the obvious (Kress 1985). Disease and illness continue to be a site where meaning is strenuously contested, with the definition of each term being influenced by the frame of reference of the speaker. For example, within scientific medicine, with its basis in positivism, these two terms are frequently used synonymously. Illness is defined as:

... a state of disease or 'dis-ease'. As such, illness may consist of a biological entity such as a cyst or tumour or some other disturbance in normal physical functioning. Alternatively, the illness may be wholly or partly psychological. (Peterson et al. 1992, p. 374)

Alternatively, within the constructionist paradigm the two terms have fundamentally different meanings. Disease is defined as a malfunctioning of physiological and/or psychological processes (Kleinman 1980). Illness is defined as the psychological experience and meaning of perceived disease. Illness is not restricted to the individual's response but also incorporates family and social responses as well as interpersonal interaction and communication within the context of the family and a social network.

Illness refers to how individuals and members of the family or wider community perceive, live with and respond to symptoms and disability (Kleinman 1980). The contemporary use of metaphor within these sites frequently results in moral judgements being made about those who have a disease. In the introduction (itself a metaphorical representation of health and illness) to her essays which focused, first on cancer and tuberculosis and then on AIDS, Sontag (1991, p. 3) commented "... it is hardly possible to take up one's residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped".

Discourse

The term discourse has been used in a variety of ways. For example, Potter and Wetherell (1987) report that the term has been used to include all forms of talk and writing (e.g., Gilbert & Mulkay 1984), to refer to the ways talk is meshed together (e.g., Sinclair & Coulthard 1975), and to much broader, historically developing, linguistic practices (Foucault 1972). In this thesis the term discourse will be used to refer to a coherent way of describing and categorising the physical and social worlds, and consisting of patterns of words, figures of speech, concepts, values and symbols. In this sense, a discourse goes beyond mere description of an object (person, social group, or event of interest), categorising it, constructing it and giving it meaning. This poststructuralist concept of discourse combines the structuralist semiotic concern with the form and structure of language, and the ways meaning is established, with the understanding that language is embedded in social and political settings and used for certain purposes rather than existing in a social vacuum (Lupton 1994a; Petersen 1994).

Discourses bring phenomena into sight, allowing things to be seen that are not 'really' there. Once an object has been elaborated in a discourse it is difficult not to refer to it as real (Parker 1992). For example, the empirical literature reviewed in Chapter One, along with the intervention practices of health care professionals based on the knowledge developed from these empirical studies, forms an integral part of the discourse of anticipatory grief. The concept continues to be accepted as 'real' despite the existence of evidence demonstrating its limited conceptual and empirical underpinnings (e.g., Bourke 1984; Siegel & Weinstein 1983), the accumulation of inconsistent data concerning its effects (Rando 1986a) and discursive analysis that it is a socially constructed phenomenon

rather than intrinsic to the process of facing an impending loss (Fulton, Madden & Minichiello 1996).

An integral and intertwining relationship exists between discourses and practices. That is, the way phenomena are symbolically represented is inextricably linked with the actions and activities surrounding these phenomena (Lupton 1994a). For example, the ways in which cancer are medically described and visually represented serves to reinforce the Cartesian mind-body dualism of Western medicine and the objectification of the disease. In turn, this tends to make an explicit separation between the disease and the body of the individual in which the cancer is situated. The primary aim of treatment practices (e.g., surgery, chemotherapy and radiotherapy) is the eradication of the cancer cells. Although consideration is given to minimising the effects such treatment has on other parts of the patient's body, life style or self-image, treatment is given ascendancy over side effects for the patient. For example, healthy tissue is also affected by chemotherapy and radiotherapy. Surgical procedure may result in restrictions in bodily movement and/or functions (e.g., colostomy) and in considerable physical disfigurement (e.g., mastectomy, vulvectomy, and orchidectomy) as well as emotional turmoil. In turn, these treatment practices reinforce the separation of disease and body. Similarly, members of the community also objectify the disease and make an explicit separation between disease and other aspects of the body or self by referring to the disease as 'it' 'the' cancer, 'the big C', or 'Cancer'.

A discourse is not discrete but refers to other discourses, overlapping in a complex inter-relationship (Lupton 1994b). Furthermore, discourses entail and presuppose other discourses to the extent that contradictions within a discourse open up questions about what other discourses are at work (Parke 1992). For example, in the discourses of cancer and HIV/AIDS there are beliefs about the life-threatening nature of each disease. Even at a time when the inevitability of death is acknowledged and accepted, the contradictory belief that 'while there's life there's hope' is also held by healthy and unhealthy individuals within the lay community and by members of the medical community. The conflict exists between the discourses of dying and death, which focus on a restricted future, and the discourse of hope, which focuses on an 'expanding' future. This is reflected within individuals living with a terminal disease who, although acknowledging that the disease will probably kill them, live with the hope that they will be the one that 'beats' the disease. The medical community

reflect this conflict in the simultaneously held beliefs that there is nothing more that known medical science can do for the individual and the possibility that tomorrow may bring a 'medical breakthrough'. Furthermore, the 'while there's life there's hope' belief, within the discourse of hope, is related to the discourse of the sanctity of life that incorporates the belief that human life is valued above all else.

Different discourses are available to different audiences (Parker 1992). In relation to life-threatening illness two basic types of discourse can be identified; the common sense discourse and professional discourses. As a common way of structuring the world of life-threatening disease and illness these discourses function as a perspective for different groups within the community. That is, as a perspective, each discourse leads to common attitudes and validation of common definitions of social objects relative to each group. For example, from the perspective of the common sense discourse of cancer the disease, as a 'death sentence', is perceived as reality. Alternatively, from the perspective of the medical discourse cancer can be cured if detected early.

Common sense discourse

Common sense discourses consist of knowledge, about objects, events, concepts or actions, for example, an object such as a condom, a disease such as cancer and HIV/AIDS, concepts such as grief, hope, morality, and culpability, or an action such as sexual intercourse or surgical treatment (Lupton 1994b; Parker 1992) which is shared between members of the society in what Berger and Luckman (1971) describe as the normal, self-evident routines of everyday life. These common sense discourses are descriptions of reality that 'go without saying' and their unusual moral authority lies in the fact that they are taken by 'everyone' to be beyond dispute. Common sense discourses are accepted as consisting of objective truths outside human intervention (Miller 1993). They constitute one form of reality that is taken for granted and internalised by members of the community. For example, the common sense discourse of cancer is a description of reality that is accepted by non-medical members of society (i.e., members who belong to the lay community). It provides this community with a publicly created context which informs how people talk about, and come to understand, the disease of cancer. A belief within this common sense discourse is that "... cancer is a death sentence' (Lowenthal 1996, p. 3). Although this belief is not always stated explicitly, evidence that it is still widely taken for granted by non-medical

members of the community is available in the form of the need for current national anticancer campaigns (e.g., Anti-Cancer Council of Victoria 1995, 1997b, 1997a). These information and education campaigns not only inform the general public about various aspects of the incidence and treatment of specific cancers but also promote the message, either explicitly or implicitly, that early detection of these types of cancer leads to cure rather than death.

In relation to life-threatening diseases, the common sense discourse also incorporates general knowledge concerning all aspects of the disease (e.g., cancer, HIV/AIDS), including reasons why it develops, how it is diagnosed, the types of treatment available, their effectiveness and side effects, the progress of the disease and how it affects the individual, and the individual's prognosis. This common sense discourse 'script' is 'written' or developed in a number of ways. This is particularly evident in the diseases of cancer and HIV/AIDS. For example, the common sense discourse of cancer is informed primarily by the medical discourse of cancer. That is, the nonmedical members of the community come to know about cancer through lay interpretations of medical knowledge, procedures and practices. This interpretation occurs in response to specific education campaigns (e.g., Anti-Cancer Council of Victoria 1995, 1997b, 1997a), media reports (e.g., Gray-Grzeszkiewicz 1997; Hull 1997), literature (e.g., Lowenthal 1996; Solzhenitsyn 1971; Sontag 1991), films, television, and personal accounts (e.g., Allbrook 1977; Warburg 1988). It is also informed by the processes and practices of developing a range of socially defined concepts that construct ways of viewing the world (e.g., see discussion on Health and construction of the self, page 79). However, as will be discussed in Chapter Seven, the common sense discourse of HIV/AIDS has been informed primarily by the mass media (Aroni 1992; Lupton 1994b).

The common sense discourses of cancer and HIV/AIDS empower lay members of the community, who do not have either disease. It does so by providing them with ways to talk about, and understand, both the discourse object (the illness experience) and discourse subjects (individuals who have the disease). Furthermore, it sanctions the forms of social interaction with those individuals diagnosed with these diseases by defining, describing, and delimiting expectations concerning verbal and non-verbal responses regarding the diseases and illness experiences. Since these discourses are not discrete, this interaction is

also influenced by a number of other closely related discourses (e.g., hope, grief, dying, death and stigma). The common sense discourse also defines how individuals with the disease should respond to all aspects of the disease and illness experience. These 'definitions' may be explicit or implicit. Moral judgements implicit in the language and metaphors used, within the common sense discourse, to make meaning of the disease, along with the practices within this discourse actively promote the separation of the individual living with these diseases from those members of the community who are 'healthy'. Consequently, these discourses serve to maintain the boundary between healthy members of the community and those who are unhealthy. At the same time, it does not endow individuals with the disease the right to speak openly about their experiences. Rather, through the related discourse of hope it identifies the limited ways subjects of the discourse (i.e., individuals with the disease) can speak about their experiences. Thus, by restricting the individual's right to speak openly, the common sense discourse marginalises the individual living with a life-threatening disease. This oppression of the individual to speak freely about their experiences is also related to the common sense discourses of dying and death. However, as will be demonstrated in Chapters 5 and 7, the common sense discourse of cancer does not provide community members with appropriate ways to discuss issues with individuals diagnosed with cancer. Also, it will be demonstrated that the common sense discourse of cancer does not provide individuals diagnosed with cancer with appropriate ways to discuss their emotional reaction to their illness experiences.

Professional discourses

Professional discourses contain knowledge arising as a result of the division of labour and whose 'carriers' are institutionally defined (Berger & Luckmann 1971). For example, medical discourses consist of knowledge developed by various groups within the specialised institution of medicine and are used to categorise, construct and give meaning to phenomena. As an alternative to common sense discourses professional discourses make claims about the world that tend to be less inclusive of social life (Miller 1993). For example, some individuals living with a life-threatening form of cancer are able to counter the medical professionals assessment of a terminal diagnosis by moving outside scientific medicine and turning to 'alternative' therapies that offer different definitions of the 'problem' and different treatment programs (e.g., stringent diets, ground coffee enemas and strict meditation regimes).

Professional medical discourses are used by members of the medical community in the everyday conduct of their profession. These medical discourses are recognised in the specific patterns of words, figures of speech, concepts, values, symbols and practices used by the various groups within the medical profession to categorise, construct and give meaning to the disease of cancer. Although medical members of the community are able to distinguish between these multiple medical discourses the distinction is less obvious to members of the lay community who incorporate medical knowledge under the general term 'medical discourse'.

As opposed to the common sense discourses of life-threatening diseases, which is based on general knowledge, the medical discourse incorporates specific knowledge, primarily developed on the basis of the scientific terms of the biomedical model. This knowledge includes all aspects of cancer, including the range of diagnostic tests and their application, identification of different types of cancer, whether it is a primary cancer or one that has metastasised and become a secondary cancer, how the disease progresses, its effects if left untreated, which secondary sites are associated with each primary cancer, the full range and types of medical treatment, how treatment affects the patient and the prognosis for each type of cancer. This medical knowledge is developed through clinical investigation of all aspects of each form of cancer and transmitted to other members of the medical community through specific professional medical training, scientific articles published in specialty journals, and conferences and seminars.

The medical discourse empowers members of the medical profession by providing them with specific, stylised ways of talking about and understanding the discourse object (the disease of cancer or HIV/AIDS) and the discourse subjects (cancerous tissue, the HIV, patients with cancer or HIV/AIDS). In defining, describing and delimiting what it is possible to say and do and what it is not possible to say and do the medical discourse also sanctions the form of social interaction not only with individuals with cancer or HIV/AIDS but also with other members within the medical profession (e.g., between medical specialists, general practitioners and nurses).

Conceptual differences between common sense and medical discourses

Cancer and HIV/AIDS is conceptualised in two fundamentally different ways within each discourse. The common sense discourse focuses on cancer and HIV/AIDS as an illness experience. That is, it concentrates on how the sick individual and members of the family and wider social network perceive, live with and respond to the symptoms and disability caused by the various forms of cancer and HIV/AIDS. Illness problems are the principal difficulties that symptoms and disability create in the lives of individuals diagnosed with a disease.

On the other hand, the medical discourse focuses on cancer and HIV/AIDS as a disease based on theories of disorder. Kleinman (1988, p. 5) suggests that disease is "... what practitioners have been trained to see through the theoretical lenses of their particular form of practice". In other words, the medical practitioner reconfigures the patient's and family's illness problems as specific technical issues. The individual's health problem is interpreted within a particular nomenclature and taxonomy, a disease nosology that creates a new diagnostic entity; an 'it', the disease (Kleinman 1988).

Individuals' interpretation of the medical discourse

Under routine circumstances, access to the specialist knowledge contained within the medical discourse is not readily available to non-members of the medical profession. However, the trend toward medicalisation of social problems results in more lay members of society engaging in interaction with the medical discourse. This is not to suggest that non-medical members of society become fluent in the knowledge within the medical discourse (despite some individuals wanting to know 'everything' about their particular form of disease). Through interaction with medical professionals individuals are introduced to a variety of professional medical discourse elements which they symbolically designate as objects. Individuals then act toward these objectified aspects of the professional discourse based on the meaning the individuals have ascribed to them. For example, individuals are generally introduced to the medical discourse of life-threatening cancer at some time during the diagnostic process. In some instances the symptoms prompting the initial medical consultation may be sufficiently specific for a general practitioner to make a preliminary diagnosis of a life-threatening disease. Although they may not fully

comprehend the medical terminology or practices used during this encounter, individuals apply their own symbolism to these new words, concepts and practices.

Alternatively, the general practitioner may not be able to confirm the diagnosis, or results of routine preventative procedures (e.g., Pap smear) may be inconclusive, and the individual may require referral to a specialist medical practitioner for further diagnostic tests. The practice of referral to a specialist is also objectified and ascribed symbolic meaning by the patient. For example, the medical practitioner may see this practice as simply sending the patient to see someone who has more, specialised knowledge in a particular area of medicine or access to specific diagnostic tests. However, the patient may perceive referral to a specialist as symbolising that their health problem is of a more serious nature than first appeared. This referral provides the opportunity for individuals to engage in further interaction with different members of the medical profession and a wider range of elements of the medical discourse. In turn, these new elements of the medical discourse are symbolically designated as objects and increase the individual's range of medical 'objects' toward which to act.

Once diagnosis is confirmed and a treatment program initialised the individual with cancer is again introduced to further elements of the medical discourse. Surgical treatment generally requires informants to be hospitalised for several weeks. Some forms of chemotherapy and radiotherapy also require hospitalisation for varying lengths of time. Other forms of these therapies are conducted on an outpatient basis. Hospitalisation and outpatient visits also provide the opportunity to engage in more interaction with different members of the health care profession. Activities within hospital are also perceived as elements of the medical discourse and ascribed symbolic meaning by patients. Through these personal experiences individuals are inevitably drawn into more interactions with a wider range of elements of the medical discourse and practitioners who use it. As a consequence, sick individuals are introduced to an increased range and quantity of elements within the medical discourse. In each interaction individuals symbolically designate new elements of the medical discourse as objects. In addition, on the basis of new experiences, individuals may vary the symbolic designation of previously encountered elements of the medical discourse. Individuals act toward all these objectified elements of the medical discourse on the basis of the meaning these individuals have ascribed to them.

This interaction constitutes individuals' construction of the medical discourse. Since this thesis is concerned with understanding the potential for action among individuals living with a life-threatening illness it is necessary to understand the world of objects that these individuals have symbolically designated. Individuals living with a life-threatening illness define their situation in terms of the relevant cluster of objects associated with life-threatening illness and of the dispositions to act that these imply. This definition of the situation serves as a general frame of reference for individuals within which they assess the consequences of particular lines of action. Consequently, this thesis is not concerned with the professional medical discourse. In contrast, the focus of this thesis is the 'medical' discourse as constructed by individuals living with the life-threatening diseases of cancer and HIV/AIDS.

Discourse and power relations

Discourses provide frameworks for debating the value of one way of talking about reality over other ways (Parker 1992). For each group within society the relevant discourse defines, describes, and delimits what it is possible to say and not to say (Kress 1985) and, by extension, what it is possible to do and not to do (Lupton 1994b). For example, the common sense discourse of cancer not only describes, classifies, and categorises a society's everyday knowledge concerning cancer, but also constructs and gives meaning to the disease in lay terms to facilitate understanding for general members of a society. At the same time this discourse, either explicitly or implicitly, delimits what is possible to do and not to do concerning cancer. Similarly, the medical discourse of cancer, using specialised knowledge developed by the institution of medicine, not only describes the medical aspects of cancer but also categorises, constructs and gives meaning to the various forms of cancer for members of the institution of medicine.

Discourses are powerful and have political functions: as a perspective they attempt to persuade audiences to accept a particular version of reality over another (Lupton 1994b; Parker 1992). For example, in the area of Australian health care there are a number of different 'communities' or groups interested in health care (e.g., health care providers, health care recipients and the bureaucracy). These groups categorise and describe knowledge of health care in different ways and use a particular discourse in attempts to

sway non-members of their group concerning the veracity of their particular version of reality. The bureaucratic discourse may focus on the financial aspects of health care and be used in attempts to persuade non-bureaucrats that this is the ultimate version of reality. Similarly, the health care provider discourse may focus on identification, treatment and cure of diseases and be used to convince others that this is the most important reality of health care. Finally, the health care recipient discourse (common sense discourse) may focus on making sense of the disease on a level that is of concern to members of the society on a day-to-day basis.

Miller (1993) suggests two consequences flow from the fact that common sense discourses are so securely installed as the 'natural' order. Firstly, it is more difficult for individual members of the community to resist or challenge such discourses or voice an alternative discourse. For example, it is difficult to resist the belief that 'cancer is a death sentence'. Secondly, social problems theorists are less likely to see routine, everyday conversations as sites of social problems. However, these sites are of interest in the poststructuralist approach to social problems. They indicate sites where "... the power of dominant discourses to silence resistance and to mask the achieved character of this outcome is greatest, because it is the most perfectly hidden" (Miller 1993, p.362).

The work of Michel Foucault (1926-1984) is particularly useful in the examination of power relations within the area of health and medicine. The important difference between Foucault's concept of power and that of most social science, particularly in western societies, is twofold. Firstly, rather than being possessed by a particular group within society (e.g., the state, men, or owners of economic enterprises), power is exercised throughout the whole of society. In the medical context power is a strategic relation which is diffuse and invisible rather than a unitary entity (Lupton 1994a). For example, the belief concerning the importance of medical testing, constant monitoring, invasive or embarrassing investigative procedures and, in the case of cancer, radical and often painful treatment procedures in the interests of the patient is part of both the professional discourse of medicine and the common sense discourse of medicine. Explicit coercion is not necessary under routine circumstances as patients voluntarily submit their body to the gaze of the medical, or health care, professional. This interaction takes place because both parties have been socialised to expect such interaction. Secondly, Foucault's concept also

gives more attention to resistance by subordinated groups in specific institutions than is evident in much existing critical sociology, thus allowing the identification of many sites for resistance and change (Petersen 1994). This is particularly relevant to the issue of HIV/AIDS. More than any other issue in the last two decades HIV/AIDS has called into question the established systems of medical authority (Altman 1992b). The rise of well informed community groups associated with HIV/AIDS, and the inability of medical science to eradicate the virus or cure infected individuals, has ensured the rise of tension over the definition of expertise as it related to this new disease (Altman 1992b; Plummer 1992).

Foucault (1982) was concerned with how the conduct of individuals or groups might be directed or governed through the production of knowledge. He saw power generated by knowledge which constituted people as 'subjects' and then that knowledge being used in governing these subjects (Foucault 1971, 1977, 1981, 1994). For example, one aspect of the power of medicine rests in the development of knowledge about, and reaction to, diseases. In practical terms medical knowledge and practice defines categories of patients' responses that are deemed functional and those that are deemed dysfunctional or pathological. In this sense, power is not necessarily a subjugating force aimed at domination, but is closer to the idea of a form of social organisation which, through voluntary means, maintains social order and conformity (Lupton 1994a). Furthermore, language is structured in such a way as to mirror power relations so effectively that, frequently, other ways of being are marginalised or invisible (Parker 1992). For example, current grief-related 'medical' knowledge incorporates language that implies that the concept of anticipatory grief is 'real' and that to believe otherwise is inconceivable. Engaging in the process of anticipatory grief is described as 'adaptive', 'functional' and 'normal' and those individuals who do not engage in anticipatory grief are described as 'failing' to engage in the process and, therefore, 'dysfunctional', 'maladaptive' or 'in denial'. Use of language in this way supports the implication that there is no other way of being in relation to an impending loss; it is not possible to consider individuals who do not engage in anticipatory grief as functional or normal.

Health and construction of the self

The healthy self

Historically, health and longevity, as the objects of philosophical and folk wisdom, religious incantation and prayer, and the counsel and admonition of healers, have been central values in Western thought (Crawford 1994). Furthermore, during the eighteenth century, with the embrace of science and its promise of the discovery of the laws of life, health became a social and individual project of considerable importance. Health emerged as "... an avowed goal of scientific investigation and medical practices, an object of public policies, institutional and familial concerns, and a widely espoused and adopted individual pursuit" (Crawford 1994, p. 1349). By the nineteenth century health was understood as the outcome of scientifically informed practice upon a natural body. It had become a key word that was written and spoken about medically, socially and philosophically. As a social ideal, health became the basis of debates about the relative importance of religious and secular world views. Furthermore it became an essential foundation of character for the middle class, and a widely accepted responsibility of the state and the individual (Foucault 1980; Haley 1978). The increasing incorporation of a variety of dimensions of society into the domain of health and the medicalisation of deviance amplified the defining power of health in relation to the self and the other. Thus, the emergence of medicine signified the advent of health as a primary social and personal goal (Crawford 1994). Furthermore, with the separation of mind and body came a new kind of knowledge; an understanding aimed at mastery and control of the body, at maximising its potential and putting it to more efficient and instrumental use (Foucault 1977). The multiple scientific investigations, that began to coalesce under the mantle of medical purposes, developed as a science aimed at knowing this newly objectified body. Using a range of conceptual and technical operations focussing on description this newly emerging medical science developed health as a concept for describing the normal state of the body. This description became the goal, that is, the restoration or maintaining of normal functioning (Crawford 1994).

Foucault (1980) emphasized how the health of individuals came to be regarded as a criteria for a good society and good government. The traditional pastoral power of the Christian church, which was premised on the achievement of eternal salvation for the individual, acquired more secular forms and aims. A new discourse developed around the enhancement

of the individual. Health became one of these aims; a secular salvation promoted by secular institutions. The family was one such institution. It became a primary site and agent of medicalisation. That is, it became a site where notions of individual and social well-being and deviance were internalised and diffused (Crawford 1994). The family began to be perceived as an institution which was obliged to undertake the proper development and protection of the health of its members. Thus the family was designated as a site where the physical body would become the object of a more finely tuned attention and a more concerted, medically informed and directed, practice. This was achieved through the physical body becoming increasingly mobilised into regimes of diet, sexual control and physical development (Crawford 1994). Consequently, the family assumed more of the responsibility of social control in the containment of a proliferating series of 'deviancies' (Donzelot 1979).

In the name of health a number of conceptions, aims and practices converge and contribute to shaping the modern individual. Crawford (1994, p. 1351) states that "... the new self, for which health would achieve an almost sacred quality, came to be understood as a discrete individual detached or abstracted from the ascribed roles and expectations of moral personhood rooted in tradition". Throughout the social body, health legitimised an expanding series of practices which enhanced the observation and monitoring of individuals. At the same time, it brought more individual behaviours, attitudes and dispositions into the sphere of concerted action for social and individual improvement. It also extended social control through a detailed identification of deviations from the healthy norm. This medical-moral control in the name of health relied on the self-regulating practices of the individual pursuing aims of self enhancement (Crawford 1994). Health became a rich source of metaphor. It can be understood as a metaphor for self-control, self-discipline, self-denial and willpower (Crawford 1984). This capacity to condense and express a wide range of meanings added momentum to the pursuit of health. Crawford (1994) argues that:

Health provided ample opportunities for the demonstration of character. The healthy individual, for example, was a person who, in resisting immediate gratification, took command of his or her life possibilities. The 'new man' [sic] would not only mobilize his body for the competitive struggle, he would also acquire a body and a longevity commensurate with his self-designated role in history. Thus, the pursuit of health became an arena for the display of the

growing bourgeois ideal of taking responsibility for determining one's own future. (p. 1352)

Crawford (1994) also argues that health continues, in the late twentieth century, to be a moral discourse, an opportunity to reaffirm the values by which the self is distinguished from the other.

The unhealthy other

Critical illness is a symbolically charged event as it represents a danger not only to individuals but also to the social order. Illness threatens to disrupt the healthy individual's everyday activities, obligations and social roles on which identity largely depends (Cassel 1982). Furthermore, it threatens the individual with the prospect of varying degrees of disorientation and multiple losses (e.g., loss of control, loss of privacy, loss of income, and loss of normal activities). Life-threatening illness sets in motion psychological defences. Gilman (1985) suggests fear of death or dissolution and the defence it engenders provides and explanation for why the seriously ill person is seen as different:

It is the fear of collapse, the sense of dissolution, which contaminates the Western image of all diseases, including elusive ones such as schizophrenia. But the fear we have of our own collapse does not remain internalized. Rather, we project this fear onto the world in order to localize it and, indeed, to domesticate it. For once we locate it, the fear of our own dissolution is removed. Then it is not we who totter on the brink of collapse, but rather the Other (p 1).

For the healthy individual, the fear of loss of control and fear of death gives rise to a defence. This defence takes the form of a projection onto the unhealthy; a perception of the afflicted as particularly susceptible due to their distinctive behaviours, emotional predispositions, social or geographical environment, or unexplained susceptibilities believed to be the property of groups (Crawford 1994). In this way death is kept distant, far from the 'natural' or 'normal' vitality of the healthy self. The many metaphors concerning illness frequently make moral judgments about the individual and, simultaneously, are often perceived as a way of taming death (Sontag 1991). The sick are not only made responsible for their illness, but also made different (Crawford 1994). The loss of health leads to a setting apart from those who are healthy and, consequently, to a loss of identity. The claim of health is also a declaration of identity: 'I am responsible and rational', 'I am in control of my body and my life.' A healthy body is owned by the deserving individual.

Consequently, illness must have a cause located outside the normal self, for example, in deviance from the rapidly expanding mandates for healthy behaviour, in a fatal flaw of character or personality defect, in an unconscious predisposition toward illness, and living in a 'stressful' environment with poor 'stress' management (Crawford 1994). This notion of health as the property of the normal self is powerfully reinforced by the association of HIV/AIDS with illicit drug use or an illicit, promiscuous, or extra-marital sexuality. So too with cancer and its metaphors of mystery and malevolence that reinforce separation from the normal, healthy self to the degree that people with cancer find themselves being shunned by relatives and friends. Furthermore, they frequently become the objects of practices of decontamination by members of their household, as if cancer, like HIV, were an infectious disease (Sontag 1991). The sick are perceived as essentially different, lacking the discipline and willpower to maintain or restore health. This social distancing from the unhealthy is a form of stereotyping of already stigmatised groups (e.g., homosexuals and intravenous drug users) who, because of their 'irresponsible' habits or lack of care for themselves, then become confirmed in their otherness. In effect, the healthy, who have come to invest so much in their health, buttress their immunity against illness by constructing a quarantine of identity against the unhealthy (Crawford 1994).

Illich (1976) refers to a 'cultural iatrogenesis' whereby a medicalised health undermines the cultural and individual capacity to embrace and respond to pain and suffering. At the same time it creates distance between the self that is healthy and the other who is unhealthy. Health has become the expression of a technological dream and serious illness has increasingly become the shadow world of that dream. Medical experts, as guardians of the division between life and death, ensure that, with the individual's responsible cooperation, the boundary is not crossed until absolutely necessary. Even when this occurs the crossing will be facilitated by the new therapeutic technologies (Arney & Bergen 1984). Unable as a culture to maintain a close proximity to illness, decline and death we are unable to mirror our own fate. In a flight from death, rather than living toward death, the healthy self mobilises all available resources to fend off the threat of dissolution. Thus, the unhealthy come to represent the inevitability healthy individuals would deny for themselves (Crawford 1994).

Crawford (1994) argues that serious illness also poses a danger to the social order. The individual's disorientation through serious illness is simultaneously a disordering of social relations. The sick person is "... plunged into a vortex of the most fundamental questions concerning life and death. The everyday routine of more or less uncritical acceptance of the meaning of life is sharply interrupted by serious illness" (Taussig 1980, p. 4). Conventional understandings are 'destructured' as the seriously ill individual queries the basic personal, social and moral implications of the illness. The 'how' questions, that can be answered by medical science, are given less consideration by the individual than the self-definitional questions 'why me?' and 'why now?'. These questions signify a crisis of self-definition that is created by illness. In turn, illness raises questions about the adequacy of conventional expectations and structures within which not only the self had previously functioned but also within which everyday social relations operate (Crawford 1994).

There are strong motivations at both the social and individual level to represent the sick as different. The defensive position, for the social order, is the deflection of social problems and resentments away from their structural social source and onto the pathologies of the individual (Crawford 1994). At the individual level the defensive move is not only a denial of vulnerability and loss of control, but also an attempt to preserve the individual's privileged place in existing social relations. The otherness of the sick is a boundary maintaining device (Crawford 1994)

Implications for the ill person

This dichotomy between the healthy self and the unhealthy other has implications for individuals living with a life-threatening illness. These individuals who, prior to their diagnosis undoubtedly used the socially acceptable concept of health, either consciously or unconsciously, to conceptualise the self within the wider, accepted society, must now face the task of incorporating the socially stigmatised, unhealthy other. The dilemma for the individual is how to incorporate the socially unacceptable other into a reconceptualisation of the self. This task is likely to be particularly difficult given the strength of the moral judgments, about the individual, implicit in the metaphors associated with illness and the negative perceptions about illness discussed above.

Conclusion

This chapter has provided some important concepts which will be applied to the analysis of understanding individuals' experiences of living with a life-threatening form of cancer (see Chapters 5, 6 and 7) and HIV/AIDS (see Chapters 8 and 9). The following chapter discusses the appropriateness of the research design given the research questions and the conceptual framework used in the current study.