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Coping with cancer: Strategies for dealing with terminal illness.

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COPING WITH CANCER: STRATEGIES FOR DEALING WITH TERMINAL ILLNESS

by

BEVERLY ROSA WILLIAMS

A DISSERTATION

Submitted to the graduate faculty of the University of Alabama at Birmingham,
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy

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2002

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ABSTRACT OF DISSERTATION
GRADUATE SCHOOL, UNIVERSITY OF ALABAMA AT BIRMINGHAM

Degree Ph. D. Program Medical Sociology

Name of Candidate Beverly Rosa Williams

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Title Coping With Cancer: Strategies for Dealing With Terminal Illness

This dissertation is an examination of the social experience of terminal cancer from the perspective of low-socioeconomic status (SES) patients. Thirty-three outpatients undergoing treatment at the Oncology Clinic at Cooper Green Hospital participated in the study. The study instrument was a 83-item, open-ended interview guide designed to gather information on patient demographics, patients' social support systems, and patients' coping strategies. Interviews were recorded, transcribed, and imported into NUD*IST, a software program for coding, analyzing, and interpreting qualitative data. Analysis of the data revealed a process of adapting to terminal illness that involved 6 phases: (a) intimating trouble, (b) delaying diagnosis, (c) experiencing the self in crisis, (d) dealing with others, (e) maintaining earlier selves, and (f) negotiating for support. Variations emerged in patients' perceptions of the social support process based on their preferences for independent, interdependent or dependent modes of interpersonal relating. In all 3 major categories of relating, however, managing the emotional burdens associated with the interpersonal dynamics of receiving care was a primary concern. Unlike other studies, which focus on caregiver burden, this research suggests that the emotional cost of receiving care may exceed the benefits patients receive.

DEDICATION

I dedicate this dissertation to the memory of my sister, Susan Rosa Rydalch, who faced death with dignity and grace. Although her life was cut short by cancer, Susan left a legacy of faith and courage for all those who knew and loved her. Like the patients in this study who told their stories in the hope of helping others understand the impact of terminal illness on their lives, Susan spent the last year of her life sharing her experience with others. Susan saw the process of dying as her final opportunity for personal growth, and she worked very hard at "getting the dying thing right." Her memory lives on in the hearts of those whose lives were touched and transformed by her spirit of giving.

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There are no words to express how deeply I appreciate the willingness of the subjects to participate in this study. At a time in their lives when they were most vulnerable, they entrusted me with the stories of their struggles with terminal illness. I am also

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CHAPTER 1

INTRODUCTION

As medical science attempted to deal with the growing prevalence of life-threatening illness such as cancer, there was increasing interest among social scientists in how individuals constructed and interpreted the social experience of dying and negotiated the final passage from life to death in contemporary society. Prior to the 1970s, medicine reserved the designator of "dying" for those patients likely to pass away during their current hospitalization, and physicians did not use the term to describe the status of individuals with incurable conditions (Sudnow, 1967). As a population, however, the dying were not an easy group to study. By the time individuals were designated as dying, they were often too physically incapacitated to participate in a sociological study. In addition, the window of time when a dying person could be surveyed, inter- viewed, and administered an instrument or scale to measure their psychosocial response to impending death was narrower than for members of other populations. It was not uncommon for subjects to die before research was complete (Sudnow, 1967).

During the last 30 years, however, the term dying came to be used, in part, to refer to the category of persons diagnosed with a medical condition that would most likely follow a downward path and terminate in death over a predictable span of time (Unruh, 1983). Within that framework, research on dying patients focused on those individuals with malignant or other incurable diseases who had a 5% or less probability of surviving 3 years (Miyaji, 1993). In contrast to this, earlier research on terminally ill persons usually focused on the period of weeks or months preceding death when aggressive, curative care was replaced with intensive, palliative care. Although all dying persons did not go through a terminal illness, the terms dying and "terminally ill" were often used synonymously in the literature (Still & Todd, 1986).

Although Elizabeth Kubler-Ross' (1969) pioneering work with cancer patients contributed to society's expanding interest in and growing sensitivity to the psychosocial characteristics of terminal illness, those following in her footsteps have made us aware of the variability which characterizes the dying experience (Kastenbaum, 1998). Because a terminal prognosis is generally made earlier in cancer patients and because physicians report more expected deaths for cancer than for other diagnoses, studies on death and dying typically focused on cancer patients (Seale, 1991). As Still and Todd (1986, p. 519) observed, "most terminally ill persons have cancer, because . . . (a terminal designation) requires sure knowledge both of the fatal course of the illness, and also of the ineffectiveness of available treatment." As the period of dying was prolonged and death more often conceptualized as a process rather than a singular event in time, a growing number of human beings were faced with the task of crafting an identity as a dying person and figuring out what is expected of them in the dying role. What Lofland (1978, p. 35) referred to as "the situation of modern dying" gave rise to normative dilemmas for both the terminally ill person and society. These Lofland identifies as the following three questions: "How shall I act?," "What shall we do?," and "What does it mean?" In response to questions such as these, notions such as "dying well" (Byock, 1997) and "quality of dying" (Wallston & Burger, 1998) offered an ideal against which to measure the individual's experience of illness and death.

The notion of a "good death" was not unique. What was unique, however, was a state of affairs in which the fear of cancer is a national preoccupation and "the anticipation of dying [is] a national experience" (Fox, 1981; Lerner, 1980; Pollak, 1980, p. 1). In the face of the cultural and socioeconomic diversity characterizing American society, however, it was a mistake to assume that all population subgroups experienced and interpreted dying from cancer in the same way. For example, in its formative stages in the United States, before third-party reimbursement became the norm, the ideology of the hospice movement appealed almost exclusively to White, middle-class populations (Paradis, 1988). Models of being sick and dying tended to focus on the need for effort and hard work, rational problem solving, individual responsibility, inner-directed goal seeking, and successful outcomes. Based on middle-class attitudes and values about life and death, such models did not adequately capture the dying experiences of low-socioeconomic (SES) groups (Cockerham, 1998; Kamerman, 1988).

While social scientists documented ethnic variation in how persons experience sickness and dying in America (Kalish & Reynolds, 1981; Zborowski, 1952, 1969), more research was needed in the social experience of dying for special populations such as low-SES groups whose coping mechanisms and interpretative frameworks did not conform to mainstream notions of what is appropriate (Mathews, Lannin, & Mitchell, 1994). It had been suggested, for example, that in order to adapt to the conditions of poverty and adjust to deprived circumstances, low-SES groups were "stretching" the general values of the larger society without abandoning them outright (Stack, 1974, p. 125). Research on the application and interpretation of the "sick role" for low-SES groups found that because of economic pressures, individuals may not embrace the sick role but continue working in spite of poor health (Kassebaum & Baumann, 1965; Kosa, Antonovsky, & Zola, 1969). Although some research findings suggested that members of low-SES groups used the sick role as a justification for poverty and disadvantaged situations (Arluke, Kennedy, & Kessler, 1979; Cole & LeJeune, 1972), no systematic work was done on socioeconomic variations in the dying role.

Statement of Purpose

Research on how persons managed life-threatening diagnoses and faced impending death focused on the role of psychosocial resources in the coping process (Somerfield & Curbow, 1992) and the importance of making meaning of the illness experience (Fife, 1995; Kleinman, 1988). Gender-, age-, and disease-based variations in perception of social support, styles of coping, and strategies for making sense of terminal illness were found (Bourjolly, 1998; Burman & Weinert, 1997; Harrison, Maguire & Pitceathly, 1995). Although scientists documented higher morbidity and mortality rates for many forms of cancer among racial minorities (Boscarino & Chang, 1998; Greenwald, Borgetta, McCorkle, & Polissar, 1996; Haynes, 1995; Stavraky, Skillings, Stitt, & Gwadry-Sridhard, 1996; van Loon, Brug, Goldbohm, & van den Brandt, 1995; Weiss, Soong, Partridge, Carpenter, & Bryant, 1997), research was mixed on the importance of race in health outcomes for low-SES populations (Bach, Cramer, Warren, & Begg, 1999; Dries et al., 1999; Keil, Sutherland, Knapp, & Tyroler, 1992; Kingston & Smith, 1997). Even though the poor were "disproportionately represented among persons coping with cancer," historically there was little research on socioeconomic and racial variation in psychological adaptation to cancer (Ell & Nishimoto, 1989, p. 444). However, recent studies found that socioeconomic status and not race was the most important determinant of health-related coping styles, attitudes, and behaviors (Mandelblatt, Andrews, Kao, Wallace, & Kerner, 1996; Paskett, Rushing, D'Agostino, Tatum & Velez, 1997). Guralnik and Leveille (1997) concluded,

> the relationship of low-SES and poor health rises to the top over and over again, across different disease outcomes, in different age groups, and in different areas of the world. The strength of this relationship has been remarkable, particularly because it has been difficult to fully explain even after taking into account important confounders such as health habits and access to care. It is also perhaps remarkable that socioeconomic differences . . . are not the focus of a great deal more research and public concern. (pp. 728-729)

The purpose of this study was to examine how terminally ill cancer patients cope with awareness of dying, interpret the dying role, and elicit support from others. To that end, I analyzed individual accounts of terminal illness among low-SES cancer patients in a public hospital oncology clinic and explored the process where by they negotiated the transition from cancer patient to dying person. This study integrated macrosociological and microsociological levels of analysis to examine how the structural constraints of poverty framed the patient's subjective interpretation of the illness experience and shaped the dying process. The research was guided by a sociological perspective on human behavior that views illness and death not simply as personal experiences unique to each individual but, rather, as organized processes, embedded in the normative structure of society, and negotiated through an interpersonal dynamic where the cancer patient is expected to assume a new role and construct a new identity.

Theoretical Perspectives and Conceptual Frameworks

Two of the major theoretical perspectives informing sociology's understanding of death and dying are structural functionalism and symbolic interactionism (Charmaz, 1980). In this study, both approaches are used to examine the normative framework that structures and gives meaning to the social experience of terminal illness. The structural functionalist perspective focuses on how the social system's organizational "needs" for maintaining order and insuring stability shape, pattern, and constrain human experience. In designing this study, I applied the work of Talcott Parsons (1951) on role theory and examined his concept of the "sick role." The symbolic interactionist approach examines the symbolic contexts and interpersonal dynamics persons employ to make sense of and attribute meaning to everyday human experience. The fieldwork of Kathy Charmaz (1983a, 1991), David Sudnow (1967), Barney Glaser and Anselm Strauss (1965, 1966, 1968) on identity construction, social death, dying trajectories, and awareness contexts inform the second perspective.

From the perspective of structural functionalism, normative structures are understood as expressions of shared expectations about desirable and appropriate behaviors within particular social groups and for society at large. Norms regulate behavior and guide individuals in their daily interactions with others. Guaranteeing conformity to norms through a system of social sanctions is an important way of maintaining social order. The sociological concept of norm is closely associated with the notion of social role or the set of norms accompanying specific positions in the social structure. Positions or statuses carry with them sets of obligations and expectations concerning appropriate behavior. When individuals or groups fail to conform to the norms of their position in the larger society, they are assigned the role and status of deviant.

Because sickness departs from the norm of good health and typically involves a certain degree of inability to maintain social responsibilities, it is considered a form of deviance subject to sanctions by agents of social control such as the medical community and the government. The requirements of the sick role provide the means of regulating patients' behaviors and those with whom they interact to insure timely resumption of normal role responsibilities. Parsons' notion of the sick role is an "ideal type" concept used to explain how individuals perceive illness, behave when sick, and engage others during the course of the disease (Parsons, 1951).

Parsons (1951) theorized four sets of social expectations associated with the sick role. First was the expectation that entrance into the sick role requires the permission of a legitimate medical authority and temporarily exempts patients from the responsibilities required of someone in good health. Based on the premise that individuals neither desire nor will their illness and cannot control its outcome, the second expectation frees patients from responsibility for the illness and authorizes others to look after them. The third expectation of the sick role views sickness as an undesirable state and obliges the sick person to try to get well. This is accomplished through the fourth expectation, requiring patients to seek appropriate medical care and cooperate with the physician. A variation on the sick role called the "impaired role" shares many of these expectations but differs in one important respect: while those with acute conditions are exempt from normal activities, those with chronic illness or impairment are expected to live as normal a life as possible (Gordon, 1966).

From the perspective of structural functionalism, death, like sickness, is a threat to the stability of society by virtue of its potential to "disrupt the equilibrium of social life" by creating a vacuum in the social structure (Blauner, 1966, p. 379). Parsons' model of the sick role contributed to the development of the notion of a "dying role" as a set of expectations and obligations related to, but conceptually distinct from, the requirements associated with being sick (Noyes & Clancy, 1977). The concept of a "dying role" was introduced in Osmond and Siegler's (1976) paper on the clinical importance of such a construct in delineating medicine's behavioral expectations for the dying individual and identifying the rights and responsibilities of the dying patient. Adapted from Osmond and Siegler (1976, p. 317), Table 1 illustrates how the sick role carries the expectation of recovery and resumption of the duties and rights associated with one's normal role. For those in the impaired and dying roles, on the other hand, adaptation to their changed health status is the normative mandate.

From a theoretical perspective, the concept of the dying role describes the expectations accompanying the diagnosis of an incurable disease and the status of the terminally ill. As Table 1 indicates, these expectations involve the right to be exempt "from *all* normal responsibilities including those of the sick role" [emphasis in original]. While awareness of dying usually begins as a psychosocial event (Kastenbaum, 1998), like entry into the sick role, assumption of the dying role typically requires official admission into the dying category by legitimate medical authority. Although the point at which an individual enters the dying process varies from culture to culture and from one disease to another, in modern society individuals are in the status of a dying person for increasingly longer periods of time (Lofland, 1978). Faced with the challenge of transcending sickness and death, the obligation of being a good patient and dying a proper death provides dying persons with a final opportunity to succeed in life (Charmaz, 1980; Kamerman, 1988). As Kamerman noted,

> If someone dies over a sufficient time, dying can become a career role. People are socialized into that role, judge themselves by the standards attached to that role, and move through their careers because of the operation of career contingencies. Dying careers, as all role careers, have a retroactive character and are also influenced by the settings in which the dying takes place. (p. 22)

Table 1

The Rights and Duties of the Sick, Dying, and Impaired Roles

	Impaired Role	Sick Role	Dying Role
Exemptions from normal responsibilities	From those directly related to the impairment	According to the nature and severity of the illness	From *all* normal responsibilities including those of the sick role
Blame	Not to be blamed for impairment	Not to be blamed for being sick	Not to be blamed for dying
Obligation	To try to live as normally as impairment allows	To try to get well as quickly as possible	To try to die with one's religious, family, legal, and moral affairs in order
Cooperation	With those helping one to become rehabilitated	With those treating one's illness and giving care affairs	With those giving care, and those helping one put one's final affairs in order
Recovery		Resumption of normal role(s) with its duties and rights	

Note. Adapted from Osmond and Siegler (1976, p. 317) [emphasis in original].

Modeled after Parsons' sick role, the sociological concept of the dying role also owes its formulation to the microlevel theoretical contributions of symbolic interaction. Symbolic interactionism is a social-psychological approach that explores the interpersonal processes in which the self emerges, identities develop, and individuals negotiate meaning. As Charmaz (1980) explains,

> Meanings of death in the symbolic interactionist perspective are assumed to arise out of the individual's experience. In turn, that experience is grounded in interaction. Furthermore, interaction is a symbolic process. In order to interact with another, a reasonably similar set of symbols from which meanings develop must be shared. In everyday life, our use of symbols emerges out of language and

> cultural understandings shared between members of a group . . . The symbolic interactionist position is predicated upon the premise that interaction consists of an interpretative process . . . and that dying persons are capable of [reflecting upon] and interpreting their worlds. (pp. 17-18)

Because the social experience of dying is often characterized by diminished interaction and a diminished sense of self, it is difficult for dying persons to keep their social worlds and social identities intact. In the face of expectations to the contrary, however, dying individuals are expected to remain themselves as they die in order to diminish the stress of their potential loss on others. Unlike structural functionalists, the symbolic interactionists do not see the social world of the dying as a static model of social interaction consisting of a normative structure with a fixed set of expectations. Instead, symbolic interactionists conceptualize norms as "perceptions of what action will lead others to validate an identity, with people conforming to norms in order to demonstrate to themselves and others that they are a particular kind of person" (Marshall, 1996, pp. 359-360). In the case of the diagnostic and treatment phases of incurable cancer, the downward trajectory experienced by patients is associated with a shifting, fragmented nature of personal identities, unclear role expectations, and a diminished sense of self. If the patient's diminishing self was not adequately nurtured and validated during the dying process, "the patient was apt to be stripped bare of self-hood" as personhood receded and social death set in (Charmaz, 1980, p. 165).

Sudnow's (1967) concept of social death bridges the macro and micro levels of analysis by describing the interaction between structural and interpersonal factors in the dying process. Dying occurs in a social order, and the notion of dying is a uniquely social one in so far as it provides a way of "attending" a person by placing a "cognitive frame of interpretation" around them (Sudnow, 1967, p. 190). As a social fact, death's parameters are defined by the practical organizational concerns of the medical establishment and the interpersonal dynamics of the social setting. In hospital settings, death is an endpoint of an orderly sequence of events structured by the patient's medical condition and the institutional tasks which it necessitates (Sudnow, 1967, p.10). The process of dying also involves an illness career in which the social self of the patient is renegotiated and redefined through interaction with family, friends, and health care providers.

Social death occurs at that point in the dying trajectory when "socially relevant attributes of the patient begin to permanently cease to be operative as conditions for treating him, and he is essentially regarded as already dead" (Sudnow, 196, p. 66). In that way, social death precedes physical death, as the social value that the dying person holds for others declines. As Kamerman (1988) explains,

> social death is the outcome of one dying-role career. Sudnow doesn't use social death in a general way, to mean being ignored or being socially isolated. It is only when that definition leads to behavior appropriate to people clinically dead that the concept applies . . . . [In Sudnow's observations] the social value of the patient was a major career contingency in moving someone toward social death: old before young, poor before rich. Consequently a person's social attributes determined quite literally their life chances. (p. 21)

In the face of social death and its absence of role, status, and identity continuity, dying patients find themselves in a unique social situation characterized by uncertain and often unrealistic expectations as well as ongoing threats to the meaning and the integrity of their sense of self. Awareness of dying is a crucial element of this dying experience (Charmaz, 1980; Lofland, 1978), for without it individuals with medical conditions that located them on a physical progression to death do not enter into the social dimension of dying or assume the dying role. As Sudnow (1967, p. 184) noted, "dying seems to be an essentially predictive term . . . seeing 'dying' is seeing the likelihood of death within some temporal perspective." When others acknowledge the patient's perception of their terminal status, the patient is able to enter into the dying role.

Glaser and Strauss' (1965) idea of awareness contexts offers a conceptual framework for understanding the interactional nature of the dying role. Using observations and patient interviews in hospital settings to explore variations in awareness of dying, Glaser and Strauss developed a typology of awareness contexts to describe what each interacting person knows about the dying status of the patient and their recognition of what others know about their definition of the situation. Based on this typology, Glaser and Straus categorize interaction into four awareness contexts which frame the interpersonal dynamics among the dying patient, their family and friends, and the hospital staff as well. In situations of "closed awareness," although the family, friends, and hospital staff know that the patient is dying, the patient is not aware of the terminal status. In the conditions of "suspected awareness," although patients suspect that death is imminent, they have not been told directly by those having the knowledge. A situation of "mutual pretense" is found when, although all involved, including the patient, know of the terminal diagnosis, everyone acts as if that is not the case. Finally, conditions of "open awareness" exist when all key players, including the patient, openly acknowledge the patient's terminal diagnosis. As Glaser and Strauss (1965) explain,

> The social and psychological problems involved in terminality are perhaps more acute when the dying person knows that he is dying . . . [and] the problem of "awareness" is crucial to what happens both to the dying patient and to the people who give him medical and nursing care. . . . When a patient *knows* he is dying, he must present some kind of dying self to the world. (pp. 5, 89) [emphasis in original]

The interpersonal stance with which dying persons face their social world reflects the social experience of dying and frequently represents a diminished self (Charmaz, 1980, p. 162). As the "dying self" struggles to present itself as a person with a coherent past, present, and future, it utilizes a "strategy of identity preservation" in order to keep its sense of self intact over time and provide survivors with a favorable image to remember after death (Unruh, 1983, p. 341).

The temporal dimension of the dying experience and the form it assumes as it unfolds over time is captured by Glaser and Strauss' (1968) idea of dying trajectories. The duration and the shape of the dying trajectory varies a great deal from person to person, with some individuals going downhill rather quickly and others either fluctuating up and down or simply lingering in a relatively unchanged condition. Expectations concerning time and certainty of death are critical factors in shaping the interaction among staff members caring for the dying and between staff and patients and their families (Glaser & Strauss, 1968). Temporal concerns such as these affect how terminally ill patients frame the social experience of dying and navigate the process of identity reconstruction. Those for whom death is certain and time of death fairly certain are in a very different type of situation than those for whom death is certain but time of death unknown. Although a terminal prognosis indicates the certainty of death, it often leaves the patient in limbo concerning the length and form of the dying trajectory. How the terminally ill fashion a dying identity and interpret the dying role in the face of uncertainty reflects their place in the social order and the cultural constraints and social expectations accompanying it (Lofland, 1978).

Review of the Literature

The individual's awareness of loss of health because of a life-threatening condition often marks the beginning of a downward trajectory characterized by a series of other losses and ending with death. It is not uncommon for patients diagnosed with terminal illnesses to suffer from an impending sense of self-disintegration, decreased mastery, and a diminished sense of coherence (Cassell, 1991). The cancer diagnostic period is a time of acute stress accompanied by depressed, confused, and anxious mood and associated with significant life disruption for patients and their families. (Andersen, Anderson, & deProsse, 1989). Cancer diagnoses and treatments are associated with significant emotional distress for a considerable number of patients, and cancer patients as a group are significantly more depressed than the normal population (Bottomley, 1997; Van't Spijker, Trijsburg, & Duivenvoorden, 1997). Research indicates that individuals with a low socioeconomic status, and especially those with the lowest level of educational attainment, are more likely to be psychologically distressed by a cancer diagnosis and to have greater difficulties in their adaptation to terminal illness than their better educated, more affluent counterparts (Ell & Nishimoto, 1989).

As predicted by the deterioration model of distress mediation (Ensel & Lin, 1991), cancer patients are thought to experience an erosion of social support over time (Bolger, Foster, Vinokur, & Ng, 1996; Wortman & Dunkel-Schetter, 1979, 1987) although this finding is disputed by some social scientists (Tempelaar, et al., 1989). The chronically ill with life-limiting conditions also report feeling a loss of self, experiencing social isolation, leading restricted lives, and suffering multiple setbacks over the course of the illness (Charmaz, 1983a, 1991). In addition, the physical decline associated with serious illness often leads to a forfeiture of employment and household roles upon which one's security and identity depend (Fitch, Bunston, & Elliot, 1999). Research on breast cancer patients suggests that poorer adjustment is associated with unemployment and lower-SES (Bloom, 1982).

One of the main characteristics of terminal cancer is uncertainty associated with illness prognosis, progression, and recurrence, as well as the impact of such contingencies on maintaining a normal life (Bertero, Eriksson, & Ek, 1997). At the outset, cancer patients are unsure about the future and worried about the lifestyle changes needed in order to deal with the physical limitations brought on by the illness and its treatment. With a diagnosis of cancer, people often question taken-for-granted assumptions and tried-and-true rules for living. Thrown into a state of ambiguity concerning the appropriate response to terminal illness, patients struggle with the complexity of the health care system, the intrusiveness of medical interventions, and the unpredictability of the illness trajectory (Mishel, Hostetter, King, & Graham, 1984). During the course of the illness, cancer patients can experience a series of remissions and recurrences of the malignancy. Understandings and expectations about the meaning of metastatic cancer often conflict or are unclear. The psychosocial impact of such occurrences on patients often leads to an existential crisis characterized by attempts to make sense of the terminal illness and negotiate meaning in the face of death (Mahon & Casperson, 1997).

Experiencing ambiguity about the right way to support and comfort the patient, family and friends are subject to feelings of uncertainty, as well (Kastenbaum, 1998). Morse and Fife (1998) found that partners of patients with recurrent or metastatic cancer exhibit the most difficulty in coping and adjusting to the changing needs of their loved ones. Bolger et al. (1996) suggested that the patient's perception of significant others' confusion and lack of emotional fortitude explains, in part, why cancer patients seek help from support groups made up of others with a similar diagnosis. While support groups are a viable alternative for those in crisis over a cancer diagnosis, research indicates that many healthcare providers do not provide patients with information about formal cancer support groups at the time of diagnosis. In addition, research findings indicate that non-white minorities seek help from extended family and civic organizations more often than whites (Guidry, Aday, Zhang, & Winn, 1997). Indeed, most long-term members of cancer support groups are female, middle class, and better educated than the general cancer population (Montazeri, Gillis, & McEwen, 1997; Stevens & Duttlinger, 1998). Field observations of cancer support groups indicate that middle-class models of coping, such as information gathering and problem-solving, are crucial for determining the appropriate ways to deal with terminal illness (Williams, 1998).

Research on the dying role suggests that, unlike the acutely ill who are required to accept a period of dependency as part of the sick role, the terminally ill are obligated by the dying role to remain independent for as long as possible (Twaddle, 1972). In a study of the social experience of cancer patients undergoing treatment, Tempelaar et al. (1989) compared cancer patients to a control group and found that the cancer patients are more likely to report positive affect and supportive reactions from others. In an attempt to explain their findings, the authors suggested that cancer patients are conforming to a socially accepted norm that make them feel as though they have to appreciate and enjoy positive experience more than other people because of a shortened life span. In addition, research indicates that terminally ill persons are expected to maintain a hopeful stance, to exhibit a fighting spirit, and to exercise a will to live in the face of declining prospects for prolonged life (Good, Good, Schaffer, & Lind, 1990). When medical prospects of prolonging life have run out, however, it becomes the obligation of dying persons to acknowledge the reality of their impending death, to view the end of their life as an opportunity for personal growth, to find meaning in their suffering, to put their affairs in order, and to achieve a peaceful closure to their life (Lofland, 1978). During the latter part of the twentieth century, however, the transition from sick role to dying role became more difficult to negotiate, as Noyes and Clancy (1977) note.

> In recent years, dying persons have been assigned to the sick role . . . . The trend toward more vigorous and active treatment of terminal patients by physicians is one manifestation . . . and, caught up in temporary treatment successes, both doctor and patient have tended to indulge in false hopes. . . . Dying persons are treated as acutely sick ones with respect to the information they are given about their disease and prognosis. (pp. 43-44)

In addition, the passage from sick role to dying role for patients with chronic illness such as cancer becomes more difficult by the lengthy period of impairment which characterizes the illness. Terminally ill individuals without symptoms of acute sickness often assume an impaired role where they attempt to restore a sense of relative normalcy. Perceiving themselves as neither sick nor dying, terminally ill, impaired persons fall into what Osmond and Siegler (1967, p. 316) refer to as "unacknowledged medical limbo."

In some countries, fear of social death exerts powerful pressure on medical staffs to delay admission into the dying role by withholding prognostic information from the patients and their families (Feldman, 1985; Gordon & Paci, 1997; Munakata, 1989). In the United States, with a powerful patients' rights movement, full and open disclosure is the norm but not necessarily the practice. Instead, we tend to see varying degrees of "disclosing" dispersed across the dying process based on the physician's perception of what the patient wants to know, needs to know, and is capable of handling intellectually and emotionally (Still & Todd 1986). As a way to buffer the effects of a cancer diagnosis for newly diagnosed patients, physicians report providing less and vaguer information about long-term prognosis while focusing, instead, on the efficacy of treatment options (Miyaji, 1993). In observations of medical encounters between physicians and cancer patients, Lutfey and Maynard (1998, p. 338) found that communication about death and dying was characterized by "interactional caution" in which physicians "unpackaged" the bad news of a terminal prognosis through "euphemistic and allusive talk."

Open awareness of dying that allows patients to exercise some control over their dying trajectory and plan their dying careers is most common among cancer patients of higher social classes (Seale, Addington-Hall, & McCarthy, 1997). In studies of low-SES patients, researchers found that such individuals knew less about their condition than more affluent, better educated patients because physicians provided more information to upper middle-class and well-educated patients (Pendleton & Bochner, 1980; Waitzkin, 1985). In addition, because low-SES patients lack education and confidence, they avoid asking questions for fear of appearing ignorant or becoming a burden (Abraham, 1993; Saillant, 1990). Mathews et al. (1994) conducted in-depth interviews with 26 rural Black women who presented with late-stage breast cancer in order to understand why they postponed seeking medical care. The findings suggest that although lack of knowledge and financial resources in conjunction with fatalistic attitudes toward cancer were factors, locally constructed explanations of health and illness also played a role. When notions from popular knowledge and folk explanations about cancer conflict with the biomedical explanations provided by health care providers, the majority of the women in Mathews' study worked out an accommodation where they held conflicting views simultaneously, calling upon one or the other depending on the context. Research among white middle-class cancer patients supported the idea that terminally ill persons construct illness understandings within the sociocultural context of their daily lives (Zlatin, 1995).

In addition to health practices, the limited research available on the health of low-income women focused primarily on psychosocial factors such as social ties, coping, and stress (Reutter, Neufeld, & Harrison, 1998), yet the social experience of dying for poor cancer patients was profoundly affected by their uninsured status. Research indicated that although Medicare coverage was available to the medically indigent for conditions where death was certain and imminent, lack of adequate medical coverage for poor cancer patients, in particular, was due in part to the uncertainties of the cancer dying trajectory and its potential for prolongation (Abraham, 1993). The effectiveness of Medicaid, the state and federal health care program for the poor, was severely limited by income restrictions and fluctuations in state and federal budget allocations. In a national study of the nonmedical assistance provided to terminally ill patients, Emanuel et al. (1999, p. 962) found that single, older, and poorer respondents were more likely to use only paid help to meet the majority of their needs and were more likely to have an unmet need for care due in part to high costs of co-payments and Medicare restrictions on home health care services. In addition, Abraham (1993) found that the poor were disabled and dying at younger ages than their more affluent counterparts, in part because

> poor patients' ailments are made worse by delay in getting care, and they show up at doctors' offices with more of what one physician called "sociomas," social problems ranging from not having a ride to the doctor's office, to drug addiction, to homelessness, to the despair that accompanies miserable life circumstances. (p. 4)

As Abraham (1993, p. 39) observed, "not only do the poor get sicker, but the sick get poorer." For many among the uninsured working poor, especially single males under the age of 65, one of the few ways to be eligible for government medical assistance was by qualifying for social security disability payments which provided significantly less income than working did.

As the literature review illustrated, the social experience of terminal cancer for the low-SES patient is associated with an intricate set of socioeconomic, psychosocial, and sociocultural factors. Attempts have been made to analyze and ameliorate their disadvantaged health status by applying economic or cognitive-behavioral explanatory models and interventions (Greenwald et al., 1996), and by developing educational and psychosocial strategies designed to meet the needs of educationally and economically disadvantaged patients (Ell & Nishimoto, 1989). Such approaches do not fully capture the complexity of the illness experience for the poor. The intersection of poverty and terminal illness gives rise to a social dynamic whose richness and pathos cannot be fully understood without entering the social worlds of the poor. Studies of special populations such as the terminally ill poor provide a window into social settings where terminal illness is only one in a series of losses and deprivations individuals and families endure. A better understanding and deeper appreciation of the plight of the dying poor can only be achieved by listening to the voices and stories of those who live it.

CHAPTER 2

SAMPLE CHARACTERISTICS, RESEARCH DESIGN, METHODOLOGY, DATA ANALYSIS, AND INTERPRETATION

Thirty-three outpatients from the Oncology/Hematology Clinic at Cooper Green Hospital participated in this study during an approximately 6-month period beginning in December 1999 and ending in June 2000. During the time of the study, Cooper Green Hospital served uninsured and low-income patients in Jefferson County, Alabama. The study sample was purposively selected; that is, it was designed to be representative of the clinic population, which was 70% Black, 30% White, 70% female, and 30% male. The small percentage of males reflected the tendency for uninsured males to present at later stages in the cancer trajectory when treatment options were more limited and when referrals to hospice were more likely. Levels of physical and cognitive functioning of potential participants were assessed by the medical director of the clinic in order to minimize the probability of selecting individuals who were unable to take part in the interview process and in order to insure the homogeneity of the study sample. Only those patients scoring above 24 on the Mini-mental Status examination and in the 80th or 90th percentile on the Karnofsky scale were included in the sample. Such scores indicate that the patients had not yet experienced any significant cognitive or physical decline from the illness or treatments.

The interviews were carried out in a small office at the Oncology Clinic during the patients' scheduled doctor visits. While some patients arrived early for appointments so they could talk with me, others took part in the interview while waiting for treatment or consultation. The clinical setting exhibited a flexible approach to scheduling that served the needs of patients, many of whom arrived late for appointments because of problems in managing symptoms and coordinating transportation and childcare. The most striking aspect of the clinic setting was its "primary group" atmosphere and its noninstitutional mode of operation. It was not uncommon to see patients and staff displaying signs of warmth and affection as they engaged in clinic routines. As a home away from home, the clinical setting generated positive affect and a sense of well-being that transcended the pathos of terminal illness and softened the rigors of therapeutic regimens.

All the major types of cancer diagnoses were represented in the sample, including cancers of the reproductive, respiratory, digestive, lymphatic, blood-producing, and skeletal systems. Malignancies of the breast accounted for one third of the cases, compared to the county and state as a whole where breast cancer diagnoses represented only one sixth of the diagnoses (Alabama Department of Public Health, 2001). More than one half of the females in the study were undergoing treatment for breast cancer, compared to the national level where one third of the women with cancer have breast malignancies (American Cancer Society, 2000). The overrepresentation of breast cancer diagnoses in the study can be attributed, in part, to the higher mortality rates for breast cancer among minorities. All the patients had a diagnosis of inoperative primary tumor or metastasises from the original site, and were undergoing chemotherapy and/or radiation treatments to reduce the size of the tumor, retard the tumor's growth, and reduce the risk of recurrence or spread of the disease.

The time since original cancer diagnosis varied from 6 weeks to 10 years, with 70% of the sample diagnosed less than 18 months prior to their interview sessions.

However, variations in length of illness did not necessarily correlate with location on the disease trajectory, with some newly diagnosed patients closer to end-stage disease than some of their clinic counterparts who had been undergoing treatment and living with a cancer diagnosis for many years. Based on the clinical judgment of the medical director of the oncology clinic, however, all of the subjects in the study had no more than a 5% probability of being alive in 3 years. Twenty-one months into the study, 17 patients, or 51% of the participants, had passed away from cancer. Another 3 of the patients, or 9% of the sample, were enrolled in hospice with a life expectancy of 6 months or less.

Selected Demographic Characteristics

Age

The sample ranged in age from 23 years to 72 years with a mean age of 52 years. As Table 2 indicates, two thirds of the sample were between 40 and 60 years of age, compared to Jefferson County and the state of Alabama, where less than one third of cancer cases occur in that age range. In 1998, the latest year for which state and county cancer statistics were available, the bulk of cancer diagnoses occurred after the age of 60 years (Alabama Department of Public Health, 2001). The relatively young age of onset of cancer among poor and uninsured/under-insured patients in this study reflects the well-documented relationship between economic deprivation and poor health outcomes. As Abraham (1993) notes,

> chronic diseases have stepped into their wake accounting for much of the death and disability among both rich and poor. The difference is that for [the] affluent, [they] are the diseases of aging, while among [the] poor . . . they are more accurately called diseases of *middle*-aging. (p. 9) [emphasis in original]

Table 2

Percent Distribution of Sample by Selected Demographic Characteristics

Demographic characteristics	*n*	Percent distribution (%)
Race		
White	10	30
Black	23	70
Gender		
Male	10	30
Female	23	70
Age		
20-29	1	3
30-39	2	6
40-49	8	24
50-59	14	43
60-69	7	21
70+	1	3
Marital status		
Single (never married)	7	21
Married	5	15
Separated	4	12
Divorced	15	46
Widowed	1	3
Common Law	1	3
Place of residence		
Own house	8	24
Rental house	7	21
Relative's house	6	18
Project apartment	5	15
Rental apartment	4	12
Mobile home	3	9
Level of Education		
Grades 1-8	5	15
Grades 9-11	11	33
High school diploma or equivalent	17	52
Post-high school training	5	15
Some college	10	30
College degree	1	3

Table 2 (Continued)

Demographic characteristics	*n*	Percent distribution (%)
Source of income		
Family handouts	6	18
Patient's disability	6	18
Patient's SSI	4	12
Patient's social security retirement	3	9
Family member's disability	3	9
Multiple sources	11	33
Employment status		
Unemployed	30	91
Employed part time	3	9
Monthly household income		
≤$500.00	9	27
$501.00 - $750.00	13	40
$751.00 - $1000.00	7	21
$1001.00 - $1500.00	4	12
Health insurance status		
Uninsured	24	73
Medicaid	4	12
Medicare	3	9
Community program	2	6
Religious affiliation		
Baptist	23	70
Holiness	3	9
Black Muslim	1	3
Seventh-Day Adventist	1	3
Church of God	1	3
Methodist	1	3
Catholic	1	3
No affiliation	2	6

Note. Multiple sources of income are the result of combining patient's SSI, disability, or widow's pension checks with the SSI, disability or retirement checks of offspring or spouses. In a small number of cases, government assistance is supplemented by patients' part-time work or the full-time work of spouses or live-in adult children. SSI = Social Security Supplemental Income

Marital Status, Household Composition, and Residential Stability

As Table 2 illustrates, 21% of subjects had never married, while 15% percent were married at the time of the study. Although one patient lost a spouse to death and another was living in a common law arrangement, the majority of respondents were either divorced or separated. All in all, 78% of the female respondents were single heads of households where they cared for themselves and others, while 60% of male subjects were unmarried but living with a close relative. As a consequence, marriage was not the primary factor in shaping the social worlds or molding the identity of the majority of the patients in this study. Indeed, for most of the respondents, the absence of a spouse was not nearly as important as the presence of a larger network of relationships forged around the ties of kinship and cemented by bounds of obligation. As Stack (1974) notes in her ethnographic analysis of kinship patterns in an urban Black community,

> Since the poor in The Flats have learned to rely on kinsmen who cooperate and exchange on a daily basis, and who live near one another or co-reside, women and children find security and support in the domestic network of their kinsmen, and likewise men, young and old, find security in their own kin networks. A man's kin may become very become very jealous and compete for money he earns, and discourage him from sharing his resources with his girl friends and their children. The incompatibility between the bonds that men and women, girl friends and boy friends feel toward one another and the obligations they accept toward kin also encourage short-lived sexual relationships. Forms of social control both within the kin network and in the larger society work against successful marriages. . . . People in The Flats recognize that one cannot simultaneously meet kin expecta-ions and the expectations of a spouse. (pp. 113-114)

The pattern of household composition among the patients clearly illustrated the importance of "family" ties in the lives of the patients and revealed some interesting gender differences in the structure of those ties. For female patients in the study, as well as close female relatives of the male patients, obligations of care giving were the defining characteristics of the household arrangements. Nearly 60% of female subjects were living in households where they were responsible for the care of immediate or extended family members, including ailing husbands; mentally ill, retarded or disabled children; dependent children; grandchildren; as well as other relatives with chronic illnesses. In contrast, 70% of male respondents were living with female caregivers, such as elderly mothers, married sisters, and wives. Clearly the burden of care fell disproportionately on females, regardless of their health, age or marital status. The realization that they were incurably ill only heightened and intensified the degree of responsibility female subjects felt for others.

In addition to strong ties of immediate and extended family, the social world of subjects encompassed the sometimes less enduring, but often equally strong, attachment generated by the geographic proximity of neighborhood and the social bonds of acquaintance and recreational association. For those 42% of respondents living in dwellings that they or a family member were purchasing or owned, the average length of residence was almost 22 years. The 15% of the sample living in government-subsidized housing units exhibited rates of residential stability and degrees of neighborhood attachment comparing favorably with the homeowners. Although they moved from apartment to apartment within the project to accommodate changing household needs, the project dwellers still averaged almost 16 years of residence in the same neighborhood. For those 33% of the sample living in other rented apartments or houses, however, the number of years in their current residence was less than half than that of the project dwellers. Finally, the least amount of residential stability was found among those who were temporarily living with a relative and didn't have a place to call their own.

Neighborhoods were more than just residential locations, however, because they not only provided patients with a sense of place, they also situated them within a context of cultural meaning and an arena of social interaction. For the individuals in this study, neighborhoods were settings where the intersection of place and sociability generated a familiarity on both geographic and personal levels, and where attachment to place intersected with the dynamics of family, acquaintance, and association. In this study, gender emerged as a defining variable in the type and quality of neighborhood interaction. For female subjects, in particular, the neighborhood served as an extended family, providing access to important psychosocial resources such as expressive and instrumental social support, sense of mastery, and internal locus of control.

For the men in the study, however, neighborhoods were experienced as focal points around which the dynamics of friendship and leisure activities coalesced and the memories of acquaintance and recreational association converged. Although kinship ties played a small role in neighborhood attachments of male subjects, peer group relationships predominated. In addition, there were feelings of camaraderie and a sense of "passing the time" which characterized the interpersonal dynamics of the male subjects which was not as evident among females. For male respondents the act of reminiscing about the good old days often provided a vehicle for becoming "street wise" and a context for framing encounters in the neighborhood and community. As Anderson (1990) notes,

> The longer people live in this locale, having to confront problems on the streets and public places every day, the greater chance they have to develop a sense of what to do without seriously compromising themselves. Further, the longer they are in the area, the more likely they are to develop contacts who might come to their aid allowing them to move more boldly. This self-consciousness makes people likely to be alert and sensitive to the nuances of the environment. . . . Social knowledge of the immediate area becomes assimilated as stories are shared and retold and a more refined group perspective emerges. (pp. 232, 236)

Education, Occupation, Income, and Insurance

As Table 2 illustrates, the levels of education ranged from 6th grade to post-secondary, with almost half of the sample reporting less than a high school education. Although 52% of participants had a high school diploma or the equivalent, and 48% had some college education or technical school training, only 1 participant or 3% of the sample had a college degree. This is in contrast to the 1998 adult educational attainment statistics for the state of Alabama that report a 78.8% high school graduation rate and a college graduation rate of 20.6% (Gaquin & DeBrandt, 2001). Occupational characteristics and work histories of the subjects formed clusters based on levels of education. Subjects whose education did not exceed 10th grade, for example, reported sporadic work histories involving multiple types of unskilled jobs in industrial and service sectors as well as extended periods of disability preceding their cancer diagnosis. Although such characteristics appeared among some better educated subjects as well, respondents who had at least an 11th grade education exhibited more stable work histories and less varied occupational characteristics than their less educated counterparts. Participants with 12 or more years of education reported working in technical jobs and quasi-professional occupations in medical, retail, office, educational, and personal care settings. The most striking characteristic of the patients in this category was the disconnect between their occupational aspirations and the realities of their employment histories.

As Table 2 indicates, all the subjects had household incomes placing them below the poverty level. This is compared to a 17.8% poverty rate for the state of Alabama in 1995, the last year for which data is available (Gaquin & DeBrandt, 2001). Regardless of educational attainment, all but 3 of the patients were unable to continue working because of the illness and treatment protocols, and none of their previous jobs provided medical leave of absence or the continuation of health insurance benefits. Some patients were not working at the time of their diagnosis because of retirement or previous disability. While a small number of patients tried to return to work full-time after their first round of treatments, they found they did not have the stamina to stay in jobs requiring them to be on their feet all day. In addition, the time consuming demands of medical regimens made it nearly impossible for patients to be dependable employees. Those few who did return to work were employed by family owned businesses where they could work when they felt up to it. As Table 2 illustrates, however, the most salient characteristic of the subjects' economic status was how they and members of their households patched together their economic resources in an attempt to meet basic needs. Because of the inadequacy of any single source of income, 33% of respondents reported seeking out and using multiple sources of economic aid, including government assistance for themselves and their disabled children, retirement pensions, and family support. In spite of the combined income of family members, the median yearly household income is between $6,000 and $9,000, compared to Alabama where the 1995 median household income was $27,357 (Gaquin & DeBrandt, 2001).

For the patients and their families, financial insecurity was exacerbated by the added expense of medical care. While 27% of the patients reported some form of health insurance, including Medicare and Medicaid, the benefits were not sufficient to cover the costs of outpatient treatments and inpatient care. The remaining 73% of the sample were medically uninsured. Because patients receiving care at public hospitals are not exempt from hospital bills, the financial situation of the uninsured and the under-insured patients became even more precarious as they got deeper into debt. As a result, the subjects' sense of mastery over their financial situation diminished as their indebtedness grew.

Religious Affiliation

As Table 2 illustrates, 70% of the subjects reported some degree of affiliation with the Baptist church, and close to 10% of respondents identified with the Holiness faith. Only 6% of the sample was not affiliated with any religion. The remaining 15% of subjects belonged to Methodist, Catholic, Black Muslim, Seventh-Day Adventist, as well as Church of God denominations. Religious affiliation and church membership played a important role in the life of the subjects, while church attendance and participation in church activities dramatically declined after a cancer diagnosis. Respondents reported that physical impairment contributed significantly to their decreased involvement in church life, but many subjects planned to return to church as their health permitted. For some patients, concerns about self-image were important factors in decisions to limit church involvement and weaken ties with church members and staff. Subjects expressed ambivalence about disclosing their illness to those at church and perceived the church setting as a place where sickness and impairment further complicated the tangled web of obligations and expectations in their lives.

Although formal attendance at church functions was affected by illness, informal religious observance in the form of prayers, inspirational and devotional readings, and Scripture reflection continued to play a major role in the life of the subjects. While the majority of the respondents prayed alone most of the time, a large number also prayed in their homes with family members or with visitors from the church. In addition, patients reported that the prayers and good wishes of others from the church, clinic, and community at large were important sources of psychosocial and spiritual support to them. The most striking aspect of these informal religious practices involved the use of telephone prayer lines and broadcast media as alternatives for or adjuncts to patients' participation in formal religious activities. Terminally ill patients were not only turning to traditional forms of prayer support but were also embracing a wide variety of religious resources to compliment or replace formal church attendance.

The Research Instrument

Participating patients agreed to be interviewed at the clinic through the use of the in-depth interview guide described below and to have the interview recorded on tape. As an instrument for research, the semistructured interview guide enables the researcher not only to format the interaction to insure that the focus of the research is addressed but also to adapt the format of the instrument to permit modifications as the process unfolds and new issues emerge. As Lofland and Lofland (1995) notes,

> a guide is *not* a tightly structured set of questions to be asked verbatim as written, accompanied by an associated range of preworded likely answers. Rather, *it is a list of things to be sure to ask about when talking to the person being interviewed.* For this reason, the interview instrument is called a *guide* rather than a schedule or questionnaire. You want interviewees to speak freely in their own terms about a set of concerns you bring to the interaction, plus whatever else they might introduce. Thus, interviews might more accurately be termed *guided conversations.* (p. 85) [emphasis in original]

The conversational nature of the semistructured, in-depth interview guide allows the researcher and the participant to mutually construct shared understandings so that the questions and responses are part of the same context of meaning (Mishler, 1986, pp. 52-65). Because they are designed to encourage and facilitate dialogue, semistructured interviews can serve as a means of eliciting narrative accounts of the respondents' lived experiences in terms which reflect the respondents' social worlds (Lofland & Lofland, 1995, pp. 81-82). As Paget (1983, p. 78) notes, the distinctive feature of semistructured interviewing is "that the answers given continually inform the evolving conversation" so that what emerges has salience and relevance for both the researcher and the respondent.

The interview sessions yielded a total output of over 500 single-spaced pages of transcribed dialogue. Although the length of the interviews varied significantly, based on the subjects' readiness and willingness to talk about their illnesses, the average time per session was 3 hr. While some patients completed the interview in one sitting, time constraints for both patients and interviewer often made it necessary to meet several times to complete the interview. Because the first part of each interview session transpired between strangers and was not a spontaneous encounter between friends or acquaintances with a shared social past, it assumed a somewhat contrived and unnatural quality that had to be overcome for the interview to progress. In light of that, the task of establishing rapport with the subjects became the most crucial element of the process. In order to do so, I found it helpful to share personal information about myself to create a climate of trust. In this process of mutual exchange I was able to discover areas of commonality with the subjects and to connect with them on deeper levels.

My capacity to sensitize myself to the social dynamic of the interview process, to discover underlying patterns of interaction, and to identify emergent themes was as important a "research instrument" as the interview guide itself. Early on in the interview process, I began to formulate an understanding of the interactional processes and interpersonal dynamics that shaped my formal encounters with the respondents. Prominent among them were strategies of self-presentation where I and the subjects alike attempted to make a favorable impression by presenting a self which we thought the other would find acceptable. In this way, the notion of being a good interviewer and a good respondent shaped the initial unfolding of the interview process and framed the context in which the opening interaction transpired. Awareness of this dynamic allowed me to appreciate more deeply the social nature of the self and to understand more clearly the intersubjective nature of the interview process. Therefore, it was important to acknowledge from the outset that the self initially presented in the interview process was not a misrepresentation of reality, but rather a reflection of the norms governing such formal interaction.

In order to guide the interview process toward deeper levels of self-revelation, I had to genuinely accept the initial selves revealed by the subjects and then gently guide them to reveal less favorable aspects of their lives. The use of positive acknowledgment and empathetic listening were the most effective ways of creating a social climate in which the subjects appeared comfortable enough to shed their initial facades and risk revealing other versions of the self. As Karp (1996, p. 37) notes in his research with mentally ill persons, if we are not able to appreciate the inner reality of others or if they are not able to share their subjective reality with us, they remain strangers to us even if we share a physical proximity with them.

> Establishing human connection is plainly linked with empathy. Social psychologists would say that we remain apart from others who will not or cannot "role take" with us; who are unable to put themselves in our place and see the world as we do. All role-taking, of course is imprecise because we can never actually be another person, we can only try to put ourselves in another's place and imagine how he or she is seeing and experiencing things. We all necessarily make distinctions among people in terms of their capacity to appreciate our inner life. Thus the decision to keep the pain of depression private casts others into the status of strangers, persons who are near and distant at the same time. They may be proximate in an immediate physical way, but they are perceived as distant because we do not share with them the perceptions and emotions that most centrally define our experience of the world.

The Research Questions

The in-depth interview guide was a vehicle for exploring patients' knowledge, attitudes, beliefs, and feelings about illness and a tool for identifying how individuals crafted an identity as patients with an incurable cancer. The guide (see Appendix A) was composed of five sections, each addressing a specific research question. Section 1 of the interview guide gathered information on the sociodemographic characteristics of the population to obtain a view of the respondent's social world. I was interested in knowing and describing the everyday circumstances of outpatients' lives in order to better understand the social context of their experience with cancer. In section 2 of the guide, I examined the temporal dimension of the illness experience. Patients were asked to describe the different phases through which they have passed since diagnosis so that I could learn how terminally ill individuals negotiate their encounter with terminal illness and adjust their identities to changing medical conditions.

Section 3 examined patients' relationships with health care providers to understand how medical information was communicated by physicians to the patients and how patients interpreted it. The purpose here was to determine the patients' understanding of the seriousness of their medical conditions and to explore their responses to the gravity of the situation. Section 4 was designed to identify the normative frames of the terminal illness experience by examining what subjects thought was expected of them as cancer patients and how they felt about their ability to live up to such expectations. Section 5 examined the coping strategies and psychosocial resources patients employed in response to their illness experiences. In this section, I was interested in understanding how those who are both poor and dying managed the dual stressors of poverty and terminal illness.

In its totality, the interview guide was a means of engaging subjects in a meaningful exchange of thoughts, ideas, beliefs, and feelings concerning their experience of terminal illness.

Methodology

The current research methodologies in medical sociology have evolved out of two major schools of thought, having roots in the rich and diverse history of the sociological enterprise. The microsociological and macrosociological approaches to research are based upon two different epistemological positions on the nature of social reality and two sets of correspondingly divergent assumptions about how best to discover, analyze, interpret, and verify findings about the social world. For proponents of the microsociological perspective, social reality is understood as an ongoing process that evolves over time, while for the adherents of the macrosociological perspective, social reality is thought of as a stable system which persists through time. Perhaps Pearlin (1992) best captures the essence of this distinction with his conceptualization of microsociology as the approach of "meaning seekers" and macrosociology as the perspective of "structure seekers." As Pearlin's terminology suggests, advocates of the microsociological perspective are interested in examining the symbolic contexts and interpersonal dynamics through which individuals make sense of and attribute meaning to human experience. Followers of the macrosociological approach, on the other hand, focus their attention on larger historical forces and social organizations shaping, patterning, and constraining human action.

Although the distinction between the two schools of thought is primarily a philosophical one, it has profound implications for the development of sociological theory and methodology, including the way in which the discipline frames and investigates the issues of health and illness. The structure seekers of the macro school take the positivist approach of the natural sciences and quantify patterns of relationships in order to test ideas about how the social structure affects health outcomes and how the outcomes vary by the individual's position in the social structure. A primary task of quantitative methodology is the challenge of operationalizing variables in order to have a measurable indicator of the frequency of their occurrence and the strength of their effect. Thus, the macro perspective uses models designed to depict theoretical connections between social structure and health outcomes, as well as a wide variety of scales whose scores are used as indicators of health outcomes. Because the aggregated data they use is at least once removed from the respondents, measurement issues of validity and reliability are of utmost concern in the quantitative methods of macrosociologists. Issues of causality and direction are problematic in the quantitative interpretation of the data, as well. Because the association between two variables is most often understood as correlational, it is not always clear in which direction the effect has taken place or if a third variable is responsible for the apparent relationship between the first two. Perhaps most problematic of all for the quantitative methods of macrosociology, however, is the fact that even if there is a strong association between two variables, quantitative analysis can only explain a part of the variation in health outcomes. While it can identify most of the pieces of the puzzle and their relative importance in the health-illness equation, the macrosociological, quantitative approach is not able to clarify or explain the process by which it occurs. Medical sociology has to look to the microsociological perspective and qualitative methodology of its "meaning seeker" sister to explore first hand the personal experiences and interpersonal dynamics of health and illness.

The microsociological perspective in medical sociology has its roots in the "Chicago School" of symbolic interaction and the pioneering work of George Herbert Mead (1934) and Herbert Blumer (1969). In medical sociology, "meaning seekers" use qualitative methods of social research, such as in-depth interviews, fieldwork, participant observation, and narrative analysis, to directly observe the social setting and to gather data on subjects' interpretations of their personal experiences. Instead of starting with an idea they want to test or a causal relationship they want to unravel, microsociologists discover emergent meaning in the data and develop sensitizing concepts to achieve a richer and fuller grasp of social reality. Blumer's (1969) notion of "sensitizing concepts" is a key component of symbolic interaction and a major tool in building theory from research findings. Sensitizing concepts function as sign posts that point to emerging themes and issues within the data. As Charmaz (1990, p.1165) explains, when an idea is used not only to "order and integrate data" but also to "ask new questions and to form new leads" it functions as a sensitizing concept.

A major methodological concern of the microsociologist is the generalizability of their qualitatively derived findings. Few social scientists utilizing qualitative methods have even attempted to make claims of statistical representativeness (Karp, 1996). Social anthropologist Margaret Mead (1953, p. 648) addresses the criticism of sampling techniques used in fieldwork and asserts that the techniques of the qualitative sociologist do not necessarily require such careful sampling in the selection of subjects in order to study cultural patterns, because "any member of a group, *provided that his position in the group is properly specified,* is a perfect sample of the group-wide pattern." [emphasis in original]. However, even with methodological limitations, the qualitative research of the microsociologist stimulates insights and ideas which can lead to further research under the more rigorous statistical standards of the quantitative, macrosociological approach. Because health-related behaviors are deeply embedded in the interaction of meaning and structure, knowledge gained through qualitative research is used to inform quantitative research, while the facts which emerge from statistical analysis can point qualitative research in new directions by identifying at-risk groups or special populations to study in depth.

Because the focus of this study is the subjective perception of the terminal illness experience, I embrace the qualitative methodology of the microsociological approach. However, in searching for meaning, I continually recognize and appreciate the effects of structural constraints in the lives of these subjects, especially those attributed to the effect of educational, occupational or residential factors on respondents' experiences of social reality. Insights from the structuralist perspective, in particular, have a special salience in attempts to think about the relationship between poverty and illness and the confounding effect they have on one's perception of his or her life choices and chances. In addition, in the construction of the research instrument, I rely heavily on the structuralist concept of sick role to better understand the notion of dying role and to clarify the impact of terminal illness on subjects' interpretations of their social worlds and their places in them. Finally, I place a special emphasis on understanding the social worlds of the respondents because of the intrinsic connectedness of the inner and outer worlds of human experience, what C. Wright Mills (1959) called "the sociological imagination"—that is, the linkage between personal troubles and public issues.

Data Analysis and Interpretation

In qualitative research, the analysis and interpretation of the data are not separate steps in the research project but part of an ongoing process beginning with a researcher's initial interest in some aspect of social reality and continuing as the researcher formulates questions and ideas about the structural patterns and interpersonal dynamics that shape it. Engaging in qualitative research requires a mind set of "watchful waiting," because it is only over time that researchers develop a sensitivity to the setting, allowing them to enter into others' lived experiences. As the dynamics of the setting unfold, researchers engage in a give-and-take dynamic with the data, applying their interpretive skills to focus and frame the analysis. As Lofland and Lofland (1995) note,

> Analysis is conceived as an *emergent* product of a process of gradual induction. Guided by the data being gathered and topics, questions, and evaluative criteria that provide focus, analysis is . . . the *derivative ordering* of the data. Because analysis is the product of an inductive and emergent process in which the analyst is the central agent, achieving this order is not simply a mechanical process of assembly-line steps. Even though there are several concrete and even routine activities involved in analysis, the process remains, and is intended to be, significantly open-ended in character. In this way, analysis is also very much a creative act. [emphasis in original] (p. 181)

The analytical and interpretive approach described above is known as "grounded theory." Developed by Glaser and Strauss (1967), grounded theory employs inductive reasoning to identify sensitizing concepts and discover insights in the data. The "ground-up" approach to analysis begins with the data and generates understandings, meanings, and interpretations of the data as the researcher interacts with it. Engaging the data in a process of interaction requires researchers to operate on two distinct but interrelated levels. On the cognitive level, it is necessary to think about one's thinking and the way it is driving the conceptual formulations emerging from the process. On the affective level, it is necessary to be aware of how data engages one emotionally to understand how the underlying emotional dynamics of the interaction process shape the interpretation of the data. As Reinharz (1995) notes,

> The self becomes the medium of acquiring knowledge . . . and the reflexive stance exploits self-awareness as a source of insight and discovery. The self can be used in research not only as an observer but also as a receiver and receptacle of experience that is to be explicated. . . . [Because] the self of the observer is always implicated, it should be converted into an invaluable tool. (p. 241)

In order to document my ongoing interaction with the data, I have recorded my reactions to research encounters in a journal. These entries are an important resource in formulating the coding scheme, not only because they provide a "social history" of my presence in the setting, but also because they reflect how my interactions with the data are shaping my interpretation of its meaning. As a reservoir of emerging insights, the journal notations point to fertile areas where an in-depth analysis could prove fruitful. While some initial insights have not withstood the rigors of the formal coding process, others have blossomed and become key elements of my understanding of the setting and its participants. As the following excerpt from the journal illustrates, my interaction with the data generates analytical schemes and interpretative frameworks that assist me in making sense of it all.

> It seems as if there is some kind of exchange of emotional burden going on here. I sense that these interviews are providing a safe place for patients to unload. But there seems to be some structure to this "unloading process" and some "rules" to follow. It is as if the patients expect me to be an active participant in the process and not just a passive recipient of their woes. I find myself offering them comfort all the time. But the strange thing about it is that they insist on comforting me as well. It is almost as if they are operating out of a perspective in which the most common commodity of exchange is emotions rather than money or possessions. This makes me wonder how emotions are used to manage their social worlds.

In another journal entry, I reflect on the emerging distinction between "private time" and "social time" that patients articulate as they talk about how they manage the emotional burden of illness.

> There seems to be a "burden of awareness" for patients as they dwell on their illness status and worry about how they will be able to cope. They talk about how dwelling on it only makes things worse, because what they fear about the future takes away the joys of the present. During "social time" they try to keep illness awareness within its boundaries so that into doesn't flood their consciousness and drown out the pleasures of the moment. During "private time" however, they are not able to keep it at bay, and they find themselves preoccupied with thoughts of impairment and death. I have come to realize that the interview sessions are in the category of "private time," and I have become a part of that.

As the above examples illustrate, the interpretation and analysis of qualitative data is enhanced when a researcher's reflections on his or her experiences in a setting serve as "sensitizing" tools in the quest for meaning. In themselves, however, such insights are not sufficient to build interpretive frameworks or explanatory models strong enough to withstand the rigors of the discipline. A more systematic investigation of the data needs to follow on the heels of these initial gleanings to insure that the researcher's subjective interpretation of the situation is solidly grounded in the realities of the objective world. In qualitative research, data analysis involves the technique of "coding," by which data is translated into categories for classification purposes. As Lofland and Lofland (1995, pp. 186-188) note, "the *cognitive* act of *assigning* a code is the first step in disaggregating your data. . . . A second step [is] that of physically placing coded data in the same place as other data you have coded in the same way." [emphasis in original]

> Coding begins the process of *categorizing* and *sorting* data. Codes then serve as shorthand devices to *label*, *separate*, *compile* and *organize* data. . . . Codes [also] serve to summarize, synthesize, and sort many observations made of the data. By providing the pivotal link between data collection and its conceptual rendering, coding becomes the fundamental *means* of developing the analysis. [emphasis in original] (Charmaz 1983b, pp. 111-112)

The Coding Scheme

Coding takes place over time and involves multiple levels of analysis. The ever-developing quality of the process allows the data to reveal its richness, complexity, and density while sustaining its groundedness in respondents' lives. As an aid in coding the data, the interviews were transcribed into a word processing program and imported into Nonnumerical Unstructured Data--Indexing, Searching and Theorizing (NUD*IST), a software package for coding and analyzing qualitative data. NUD*IST is particularly useful for creating document index systems to store, organize, code, and retrieve text. NUD*IST software assists researchers in manipulating data, in exploring relationships among categories of text, and in identifying recurring themes and patterns. Most important of all, NUD*IST provides a user-friendly approach to "memoing" or recording the emerging insights alongside the text and integrating them into the data analysis. As Lofland and Lofland (1995) point out,

> appropriate hardware and software have recently made it possible for researchers to perform coding and filing operations on a computer. The logic of coding is the same, of course, with the possible added advantage of instantaneous "filing," thus eliminating the labor-intensive acts of physically placing items of data in different physical file folders. PC data basing also increases the speed and complexity in which you can retrieve, recode, refile, and enumerate coded items and relate then to one another. (p.188)

In the initial phase of coding, "researchers look for what they can define and discover in the data" and create as many codes as needed (Charmaz, 1983b, p. 113). I have found the most productive way to carry out the first phase of coding is to begin assigning text segments to categories while still transcribing the interviews. Thinking about and organizing the data while interacting with it in the transcription process enables me to structure my emerging insights and to modify subsequent interviews in response to my developing understanding. Using the NUD*IST capability of multi-stage coding, I began the process of systematic data analysis by assigning text segments to "free nodes." As the following excerpt from the *NUD*IST User Guide* explains, the NUD*IST index system differentiates between free nodes, which are coding categories for unconnected ideas, and "hierarchical nodes," which are "tree-like" coding classifications for indicating relationships between and among ideas.

> Nodes are the containers for categories and ideas, and the links you make between the idea and the data documents. . . . Nodes can be free of hierarchical links or linked in an index tree. A project can have an index system entirely of Free Nodes. Many projects start this way, "data up," the categories coming out of the data as the researcher "thinks aloud" about its meaning. There is no limit to the number of Free Nodes, and at any stage they can be moved into an Index Tree. (Qualitative Solutions and Research Pty Ltd., 1997, pp. 74, 78)

In the initial stage of coding I classified demographic characteristics and created free nodes to store them for further analysis. As I interacted with demographic data, I began to mentally sort it and think about the relative importance of each different piece of information. For example, although I expected that age, gender, and race categories would carry considerable weight in my analysis of sample characteristics, I was surprised when religious affiliation did not emerge as equally important. As the excerpt from a memo stored in the religion node illustrates, I puzzled over the relative infrequency of patient comments on the social losses they experience when unable to attend church.

> How do the terminally ill connect with the social dynamics of the institutional church? I just don't see it here in the data. I wonder why religious affiliation does not engender social connectedness for the subjects as they face their death? In most cases, faith in God's capacity to make meaning out of suffering seems remarkably unconnected to the social network at church. Personal spirituality in the form of Scripture and prayer turn up again and again as the key elements of religiosity. It is almost as if patients are carrying "church" in their heads while foregoing the social dimension of the religious experience. I suspect the physical and social demands of church attendance function as a stressor for the terminally ill poor, and because membership is voluntary, its costs and benefits are easier to forgo. It occurs to me, however, that the church does a better and more organized job of staying connected with the grieving family after the death. It would be interesting to document this with more data.

As I moved beyond the initial categorization of traits, I began to examine, classify, and use free nodes to store segments of texts where patients expressed affect, talked about relationships, reflected on experiences of health and illness, described encounters with the health care system, and communicated attitudes about self and others. Throughout the process, I was careful to document the interplay of ideas and feelings, making note of the wide range of affective expression that accompanies everything from musings about routines of daily life to deeper reflections on life and death. While the emotional life of the patients was rich and complex, it was often expressed in terms of commonly used constructs such as frustration, fear, anger, and sadness. In most cases, however, the expression of affect was not an end in itself, but rather the means to a fuller elaboration of their thoughts about living with terminal cancer. As Lofland and Lofland (1995) note,

> to separate cognitive and emotional aspects of units— to separate meanings from feelings— is, of course, to distort the experienced world. . . . Cognitions are an integral part of feelings just as emotions are an integral part of meanings. But we separate them here . . . because to do so gives well-deserved and long-ignored emphasis on the role of emotion in human social life. Historically, social scientists have been guilty of a strong cognitive bias in their analyzes. Only in the last several decades, especially in the last several years, have researchers begun both to appreciate the fact that humans ubiquitously, routinely, and simultaneously *feel as well as think*, and to incorporate the fruits of that appreciation in their published reports. [emphasis in original] (pp.116-117)

As an important first step, the "free coding" of data is vital to the integrity of the analytical and interpretive process. Unrestricted free coding of data, however, can lead to an unmanageable accumulation of material that cries out for some organizing principle to give it coherence. After free coding all the transcripts, a recursive process involving multiple visits to each document, I was overwhelmed by the number and variety of the categories. In addition, because it is not unusual to code a single data segment in more than one category, I began to fear I would never achieve the conceptual clarity I sought.

It is at this point that a more focused approach to coding is required. Like a family who is trying to decide which household items to keep and which to include in a garage sale, I needed to evaluate the viability of each of the free codes and discard those that were not robust enough to sustain an in-depth analysis and interpretation of the data. As Lofland and Lofland (1995) note,

> as a corpus of initial coding accumulates, it becomes *itself* an object that you should review in terms of which codes are being used more than others and which topics and questions are being treated more than others. That is, one begins a process of winnowing out the less productive and useful codes and focusing in on a selected number. This selected or focused set of codes is then applied to an increasing array of data. Categories within the selected codes are elaborated. Other codes are collapsed and yet others are dropped. Some codes begin to assume the status of overarching ideas or propositions that will occupy a prominent or central place in the analysis. (pp. 192-193) [emphasis in original]

In the NUD*IST analytical scheme, researchers employ the hierarchical index system to focus and refine the coding process. After the initial stage of coding segments in free nodes, I began to explore patterns of relationships to identify how links between free nodes could serve as a basis for building a structure of hierarchical nodes. A special feature of the NUD*IST software program, hierarchical coding is an option that assists qualitative researchers in conceptualizing relationships among the data segments stored in free nodes. As the NUD*IST User Guide (Qualitative Solutions and Research Pty Ltd., 1997) explains,

> Most projects will be greatly helped by the ability to organize the categories hierarchically. NUD*IST provides the option of organizing categories hierarchically, in a "tree" of categories and subcategories. Like a library index system, or the table of contents of this manual, a tree structured system assists access to the subject area required and helps you to see the place of particular categories in the whole. To organize nodes in this way may help you clarify and explore the ideas emerging from your project. . . . In some research approaches (e.g., "Grounded Theory"), the convergence of categories or recognition of dimensions of concepts is important to the development of theory during the project. (p. 78)

Because some of the most prominent free nodes involved interpersonal issues, such as autonomy, dependency, and mutuality, I began to examine how the free nodes containing demographic characteristics were related to them. For example, while concerns about reciprocity were expressed more frequently and more intensely by single Black women, single Black men stressed the need for autonomy, while White patients of both genders focused on the need to be cared for by others. In order to conceptualize these relationships, I subsumed the demographic free nodes into three hierarchical nodes that I called the "independent mode of relating," the "dependent mode of relating," and the "interdependent mode of relating." At that point in the coding process, I was faced with two additional tasks.

The first task involved figuring out how the other free nodes were related to the 3 relational modes. While many free nodes turned out to be dead ends, those containing data on the management of affect and information emerged as important categories in my attempt to elaborate on the 3 modes of relating. While issues of affective expression and information sharing were prominent in all 3 categories, the ways that they played themselves out were qualitatively different from one category to another. For example, in the independent mode, patients avoided information exchange with others in order to minimize emotional involvement and loss of autonomy. In the dependent mode, on the other hand, patients sought out the emotional support and informational input of others to the point of mimicking their caregivers' affective tones and definitions of the situation. Finally, in the interdependent mode, patients modified the information exchange process and moderated affective expression to protect themselves and others from the relational stresses of the illness.

The second task involved identifying an overarching category for the 3 relational modes. Although the notion of "ways of relating" seemed to fit the requirement, it came across as static and one-sided. What I needed was a concept capable of capturing both the dynamic nature of the relationships and the active role of the patients in shaping the process. Returning to the free node section of the NUD*IST coding scheme, I looked for notations that would trigger insights about the nature of the relational modes. While the majority of free nodes did not provide added help, the node entitled "interaction with others" resonated with my sense that patients shaped the interaction process to meet their needs for support and care. I devised the term "interactional strategies" to describe how patients tactically manage their encounters with others to elicit appropriate support.

As a sensitizing concept, the idea of "interactional strategies" led me to examine the free codes through a different lens to make sure I had not overlooked something of significance. In the free node, "patient's perception of self in illness," I found variations in attitudes I believed would translate into important distinctions within the 3 relational modes. For example, although all the patients in the independent category attempted to disassociate themselves from the dying role by discouraging expressive or informational input from others, they used differing strategies in the process. While some of them resisted input entirely through avoidance, other "independents" dismissed the notion that anyone other than God had valid input to offer. In a similar manner, although patients in the dependent category immersed themselves in illness and readily accepted the sick or dying role, they approached it in very different ways. For example, some "dependents" relinquished responsibility for all aspects of their lives, including thoughts and feelings, while other "dependents" distressed others with their thoughts and feelings as a means of staying connected to loved ones. Finally, although all the patients in the interdependent category understood that entering the sick or dying role would have an impact on others, they used different tactics to deal with the affective and informational demands arising out of their encounters with others. For example, while some "interdependents" tried to sustain the status quo by seeking expressive and informational input from others to verify a claim of normalcy, other "dependents" tried to reshape the status quo and hold it in place by providing others with information about the illness and guidelines for thinking and feeling about the situation.

As we have seen, using NUD*IST to organize the coded data hierarchically by types and themes revealed how free node categories coalesced around a dimension of the terminal illness process I conceptualize as "interactional strategies." As a sensitizing concept, interactional strategies involve typifications of preferences for relating to others that direct patients in actively structuring the flow of information and affect in their interpersonal encounters. As Table 3 illustrates, the combination of 3 relational preferences and 2 directional styles yields 6 distinct interactional strategies.

Table 3

Typology of Interactional Strategies

	Relational Preference		
Direction and source of information and affect	Independent	Dependent	Interdependent
Directed toward patient by others	Resister type	Relinquisher type	Sustainer type
Directed by patient toward others	Dismisser type	Distresser type	Shaper type

The "independent" mode of relating to others is characterized by a preference for self-sufficient behavior and a desire to act in an autonomous manner. Independent subjects place a high value on their subjective interpretation of reality and little credence in others' definitions of the situation. As Table 3 illustrates, within this category, there are two distinct types, "resisters" and "dismissers." While resisters are on the receiving end of the affect and information that is generated by their illness, they choose to ignore it. Dismissers, on the other hand, initiate and direct the flow of information and affect toward others through a campaign of illness minimization designed to neutralize others' cognitive and affective responses.

The dependent mode of engaging the world is one of reliance on others. Dependent subjects tend to trust others' definitions of the situation more than they trust their own subjective experience of the illness. As Table 3 indicates, the 2 types within the dependent category are "relinquishers" and "distressers." While relinquishers actively seek and accept significant others' cognitive and affective interpretations of the situation and turn over control of their ideational and emotional lives to caregivers, distressers direct the thinking and feeling of significant others to insure ongoing concern and attention of caregivers. The "interdependent" mode involves a preference for relationships based on cooperation and mutual help. Interdependent subjects tend to function in an atmosphere of reciprocity where interpretations of reality are mutually constructed and sustained. As Table 3 indicates, interdependent types assume strategies of "sustainers" and "shapers." Unlike sustainers, who assume the psychosocial burden of the illness and take cues from their perception of others' capacity to deal with information and affective expression, shapers structure the illness experience with a new set of rules for thinking and feeling that frees them from their obligation to tend to the psychosocial needs of others.

For each of the 6 interactional strategies, an expanded coding scheme using the NUD*IST hierarchical format focused on the characteristic stance of each strategy toward the following subcategories: (a) self and others, (b) identity and affect, (c) primary and secondary associations, (d) medicine and religion, and (e) coping and social support. In this phase of coding, the emergence of commonalities within types and distinctions among types gives further evidence of the viability of the types as distinct approaches to negotiating terminal illness. In spite of the usefulness of NUD*IST in conceptualizing interactional strategies for coping with and managing the cognitive and affective dimensions of the terminal illness experience, there was also a disquieting sense that the strategies appeared to have a life of their own rather than being one dimension of a larger process. Relying solely on NUD*IST during the analytic phase of the research seemed to lead to a static, typology-based approach rather than a processual interpretation of the data. As Lofland and Lofland (1995) caution,

> Even though the use of PCs in fieldstudies has generated a great deal of interest and even enthusiastic promotion, in our view the virtues of computerized *analysis* (as distinct from data storage) programs have yet to be proven. . . . Indeed, our experience is that people with the strongest enthusiasm for computer fieldwork programs tend not to be the same people who are most involved in doing field studies. In our conversations with this latter group, we find that while almost all of them use PCs to store data, they also view analysis inside a computer as too confining. (p.189)

Qualitative Analysis as a Process

In an attempt to overcome some of the interpretive shortcomings of computer-generated analysis, I embarked on a post-NUD*IST phase of analysis to recode all the transcripts by hand with a special emphasis on finding a larger process out of which the interactional strategies emerged. As tedious and time-consuming as it was, this phase of coding proved to be a more effective means of tapping into the processual nature of the terminal illness experience. Framing the analysis and interpreting the data from the perspective of process rather than type of strategy located the negotiating component within an illness career and provided a deeper and richer understanding of the terminal illness experience. The notion of an "illness career" captures the dynamics of how patients move from lack of awareness to acute awareness of their terminal status, as they continually reframe their interpretation of the situation to sustain a coherent sense of self. As Karp (1996) notes in his work on depression,

> Sociologists have made good use of the career idea to refer to a range of human processes. . . .The notion of career seems an extremely useful, sensitizing concept. . . . If we conceive of [illness] in processual terms, it makes sense to adopt . . . a career model for ordering the data. (pp. 16, 55, 86)

In order to address the subjective, evaluative elements of the illness experience and attend to the manner in which patients "impose meanings onto their situation over time," Karp (1996, p.16) borrows from Everett Hughes' definition of "career" as "the moving perspective in which the person sees his life as a whole and interprets the meanings of his various attitudes, actions, and the things which happen to him." In examining how individuals with HIV adopt an illness identity, Weitz (1999) speaks to a growing trend among sociologists to conceptualize serious illness in terms of a process of biographical disruption in which awareness and interpretation of one's changed health status unfolds over time in a fairly predictable fashion. Because adopting an illness identity is "an ongoing process of meaning-making" rather than a single event in time, it is characterized by of a series of markers that identify "turning points" and critical junctures in the illness career which are often conceptualized as "clear stages in the evolution of an illness consciousness" (Karp, 1996, pp. 78, 87).

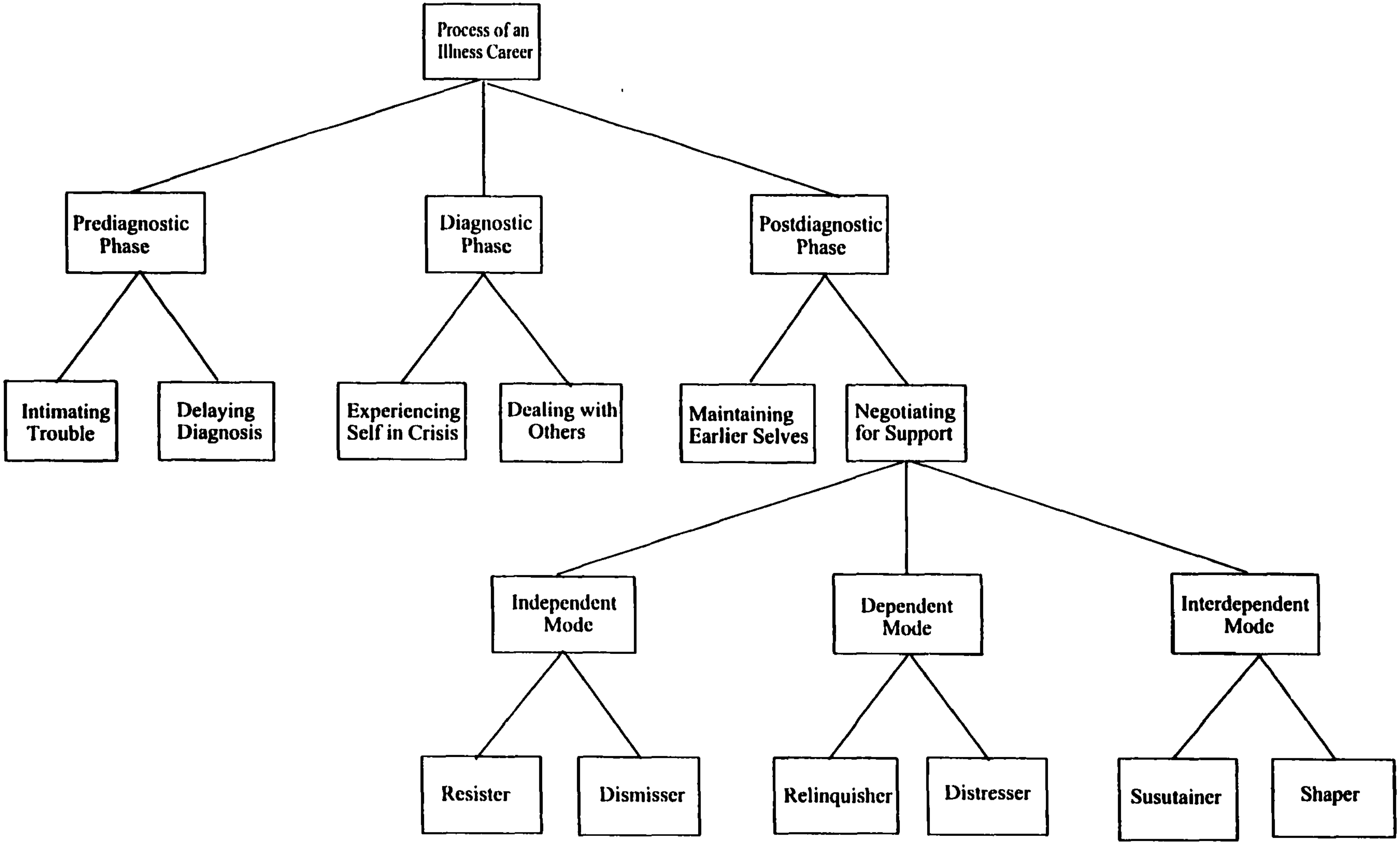

Figure 1. The process of an illness career.

As Figure 1 illustrates, the illness career for the terminally ill poor is comprised of a sequence of three distinct phases. Although I provide an in-depth discussion of each phase in Chapter 3, as a way of explaining the coding scheme, I offer a brief examination of the process here. Phase 1 of the process, the "prediagnostic period," can be best described as a time when the patients sense that all is not well but are unable or unwilling to allow a sense of foreboding to intrude into their life. As we can see in Figure 1, in the prediagnostic phase patients intimate trouble but often engage in delaying tactics or encounter barriers to care that prolong the initial stage of the process. Phase 2 of the process, the "diagnostic period," stands out as a time of existential crisis when the patients encounter threats to their personal coherence and social connectedness. Overwhelmed by fears of personal extinction and social death, patients struggle to make sense of what is happening to them. In Phase 3, the "postdiagnostic period," the patients attempt to deal with the illness over time. For the terminally ill poor, this initiates a process of normalization where they attempt to maintain earlier selves by managing the illness experience and negotiate for social support from others. As we will see in the next chapter, this process of negotiation engages others and goes to the very heart of what it means to be a social being.

As Figure 1 indicates, the negotiating component of the postdiagnostic section in the coding scheme maintains a prominent place in the analytical and interpretive scheme by highlighting the interpersonal dimension of the illness experience and identifying the different styles patients employ to minimize stress and elicit ongoing social support. As Kastenbaum (1998) notes,

> It is difficult to overestimate the importance of interpersonal relationships in the terminal phase of life. Among hospitalized patients who were likely to die within a few months, those who maintained active and mutually responsive relationships

> were found to survive longer than those with poor social relationships. . . . In a subsequent study, the same investigators found that the terminally ill patients who were experiencing the most distress were those with the most interpersonal difficulties. Not only the length of survival, then, but the also the quality of life was associated with the kind of interpersonal relationships enjoyed or suffered by the patient. This pair of studies suggests that we must try to understand both the types of interpersonal relationships that a dying person has developed through the years and the status of those relationships in the immediate situation. (p. 109)

As patients shape the contours of the terminal illness experience, they attempt to maintain "mutually responsive relationships" by engaging in interactional strategies that control access to information about the illness and define the range of acceptable affective expression for themselves and others. As we have seen, while the process of adopting the identity of a terminally ill person varies little from patient to patient, considerable variation exists in the strategies patients employ to manage their interaction with others.

Interpreting the Data

One of the fundamental tenets of sociology is the primacy of social interaction in the emergence of the self and the framing of reality. Social interaction, by definition, involves a process where actors orient their behavior toward others. In "taking the role of the other," individuals develop patterned ways of thinking, feeling, and acting that correspond to their perception of others' expectations of them. In providing a framework for subsequent encounters and interaction, these patterns of behavior solidify into predispositions and preferred ways of engaging the social world. Through the multiphased process of coding the data, it became clear that awareness of dying sets into motion an existential crisis where patients interpret their life chances and seek to control relationships with loved ones. As one patient explained, cancer didn't just happen to her, it affected her entire social world and how she experienced and engaged it.

As the coding of the data revealed, the processual nature and interactional context of the terminal illness experience provide the relevant material for a unified conceptual framework that helps us to make sense of the data. However, as a sensitizing concept and analytic tool, the notion of a strategically driven terminal illness career emerged from an in-depth examination of the lived experience of terminal cancer for a sample of low-income patients under treatment in a county hospital outpatient clinic. Any interpretations emerging from the coding process must be couched in that context.

CHAPTER 3

A PROCESS OF ADAPTATION TO TERMINAL CANCER

At the intersection of poverty and terminal illness, there is a social reality that is not well understood and is often misrepresented. Taken separately, the conditions of poverty and terminal illness are often idealized, giving rise to such notions as "idyllic poverty" and "happy death." Those who are poor and dying are frequently subjected to misleading stereotypes and unfair assessments concerning the way they live their lives or die their deaths. Understanding the subjective reality of the lives of the dying poor is not a luxury reserved for researchers and academicians, but a necessity demanded of social service practitioners and healthcare providers alike, if they are to provide appropriate health care interventions and psychosocial support to their patients. As Kieffer (2000, p. 57) asserts, "the more remote the patient's life experience is from our own, the more important it is to systematically acquire a sense of that experience— a sense of the context of that person's health." In this chapter, I use data from this study and excerpts of dialogue from transcribed interviews to contextualize the lived experience of terminal cancer and to discuss the process of adaption to terminal illness emerging out of the social world of the dying poor.

As a process for adapting to terminal illness, the model which has emerged from this research has much in common with other models developed during the last 30 years. Although most theoretical models of the dying process are not well developed or tested, the idea that patients go through a process of change over time as they cope with terminal illness is widely accepted (Kastenbaum, 1998, p. 110). The Kubler-Ross (1969) stage theory of dying, for example, explains how patients move through time from denial, anger, bargaining, and depression to some degree of peaceful acceptance. Corr's (1993) attempt to expand stage theory to address the dynamic nature of the dying process stresses the active role of the terminally ill in shaping it. Research on middle-class subjects suggests that transitions from health and illness to death transpire over time through mechanisms of self-redefinition by which patients "let go of their view of who they used to be and develop a new view of themselves and others" (Davies, Reimer, Brown, & Martens, 1995, p. 8). More recent approaches emphasize patients' subjective interpretations of the situation and examine how individuals make sense of the terminal illness experience (Fife, 1994; Jensen & Allen, 1994; Zlatin, 1995; Morse, 1997).

Analyzing the meaning-making process among special populations, however, necessitates a grasp of the cultural interpretations and shared understandings of reality that shape the individual's subjective experiences of poverty and illness. Although there is considerable research on the psychological and behavioral correlates of living with chronic illness across class lines, few studies address how the socioeconomic and cultural characteristics of special populations affect the way patients interpret and manage the terminal illness experience (Mathews et al., 1994). Becoming terminally ill is not a simple matter of assuming the identity of a dying person and adopting a corresponding set of attitudes and behaviors. Identities, attitudes, and behaviors do not just emerge out of the terminal illness experience but, instead, shape the experience around pre-existent patterns of thinking, feeling, and reacting to life crises. Rubin (1976, p. 9) suggests that responses to life events vary by social class, because the "differences in the subjective and objective experiences lead to differences in . . . [the] ways of being and doing." Reflecting on the difficulty that middle-class health workers encounter in working with the poor, Kiefer (2000, pp. 25-26) notes that "poor patients' lives are likely to be very different, and their assumptions are likely to be very different as well." Thus the "assumptive world" of the poor involves an interpretive framework about health and illness that deviates in many ways from middle-class perspectives.

The relationship between poverty and illness is difficult to unravel because each variable accounts for part of the effect of the other. The working poor "live precariously perched on the edge of financial disaster," so that all it takes to push them over the edge is the loss of work because of serious illness (Rubin, 1976, p. 205). Regardless of the etiology of illness, poverty increases its frequency and severity while diminishing the chances of a favorable outcome. Indeed, aggregate data tell us that the health of the poor is worse than that of the non-poor, and the poor continue to have a higher incidence of chronic, disabling, and fatal conditions than any other category of people (Kiefer, 2000, pp. 126-128). The overwhelming presence of economic deprivation and social inequality in the lives of the poor shape a distinctive consciousness and culture (Rubin, 1976, p. 210).

For purposes of clarity, I will discuss the adaptation process of the terminally ill poor chronologically, beginning with the prediagnostic period, moving through the crisis phase, and concluding with the normalizing and negotiating segments of the process. To inform the discussion with the lived experience of the subjects, I have selected passages for each analytical dimension which reflect the demographic diversity of the sample and illustrate the uniformity of the process across age, race, and gender lines. As the process unfolds, it is important to recall that it is not a theoretical construct imposed on the life of the poor, but an explanatory model which emerges out of the lived experience of terminal illness among low-SES populations.

Before the Diagnosis

Individuals living in poverty are well acquainted with the chronic stresses and the daily hassles of economic deprivation and social inequality that mark their lives, and they experience more than their fair share of major life events that interrupt their lives and weaken their tenuous hold on stability. The effects of poverty go beyond simple material deprivation, however, and create an environment of risk and "uncertainty" that permeates the lives of the poor and "requires a mind set that is fundamentally different from the middle-class one . . . based on the consistency of life and the unpredictability of the remote future" (Kiefer, 2000, p. 34). At any given time, the working poor are more likely than their more affluent counterparts to be trying to get back on their feet after sustaining yet another minor setback or major life crisis. As Rubin (1976, p. 29) notes, recurring struggles are the norm rather than the exception in the lives of the working poor.

> It is that temporary quality of both stability and instability in so many families that is so noteworthy. Life changes, depending on circumstances outside personal control. A lay-off, a serious illness in the family, an accident, a death — such events can thrust a stable family into instability or a while. Even in the most stable families, however, the first and fundamental fact of most of their lives was that they were poor.

There is a world of experience and a context of meaning that frames patients' perceptions of health and illness and shapes their interpretation of the physical symptoms of disease. For the working poor, cancer rarely occurs in a void or appears out of the blue to intrude into an otherwise healthy and problem-free life. Instead, patients typically report personal histories of recurring health problems or family histories of some type of cancer.

For the former, the symptoms of cancer which precede the diagnosis are interpreted as yet another chronic, but not life-threatening problem. For the latter, thoughts of cancer linger in the back of their minds, ready to emerge as a possible explanation for physical ailments. It is also possible that physicians treating the poor could operate out of a similar mind set and fail to look for cancer when there is a patient history of other health problems but no family history of cancer. It is possible, too, that an economic incentive among patients and physicians alike results in a less-serious and less-costly diagnosis. Without the benefit of a third-party payer, both uninsured patients and physicians may be reluctant to use expensive diagnostic procedures or to consider the possibility of catastrophic illness.

Intimations of Trouble

For many patients, the process of becoming terminally ill and adapting to an awareness of death begins as a nagging sense that something is wrong. At the outset of the process, the patients in this study do not have an organized sense of where their symptoms are taking them, like depressed persons lacking a frame of reference on which to hinge their early feelings of emotional distress. As Karp (1996, p. 39) explains,

> For most of the respondents, the phase of inchoate feelings was the longest in the eventual unfolding of their illness consciousness. . . . The dilemma posed for persons at this stage is that they clearly feel that something is wrong, but that it is impossible to make sense of their personal trouble until they possess the conceptual apparatus to give it meaning. Somewhere along the line people make the connection between their difficulty and depression. They may read about depression, see a list of symptoms in the newspaper that describe their feelings, or, more usually have a crisis that lands them in a doctor's office, and sometimes a hospital where their trouble is diagnosed.

Among uninsured and underinsured populations where preventive medicine is a luxury many simply cannot afford, knowledge of symptomatology is often incomplete or inaccurate, leading many to minimize, misinterpret or ignore the signs of serious illness. Indeed, many patients live with signs of trouble for long periods of time, attributing their symptoms to more familiar, self-limiting conditions not requiring medical intervention. As short-term solutions to the problem, self-diagnosis and self-medication can serve to postpone professional care past the point of usefulness of life-saving therapies. Most troubling of all, however, the inability of the working poor to access medical care can translate into a mind set that precludes the possibility of serious illness at all.

> My spleen was swollen, and I complained about my stomach, and my rectum. I would like eat food, but, I had a hard time, you know, stooling. At first I thought it was hemorrhoids so I didn't do anything about it. Then I had this aching in my shoulder. It felt like a toothache was aching, it was just that severe. I thought it was arthritis. At that time, I was giving myself ibuprofen for the pain. I never had a point of going in and out of the doctors so it may be that was the problem that, that it was an inward thing, so I never was like the sickly type. (55-year-old widowed Black woman with colon cancer)

> I sort of knew something was wrong. I thought that I maybe had an infection or something like that, because I'd been having female trouble and everything like that. That's mainly what I thought it was. I didn't think it was that bad. Then I was sick to my stomach all the time, and I just couldn't hold anything in at all, I mean, I just kept dry heaves and everything. I was depressed and everything, you know. My husband was cheating on me, and he sold my house right out from under me. I stayed depressed and everything all the time. That's why I didn't think I was really sick. I thought maybe it was just my nerves. (53-year-old divorced White woman with cervical cancer)

In spite of disquieting symptoms that have the potential to interfere with activities of daily living, patients manage to work around the problem by maintaining relative normalcy in their lives. By devising accommodations that minimize the disabling effect of symptoms, patients are able to carry on with their day-to-day responsibilities.

> I was more or less borderline diabetic, you know, and not quite, I didn't need the medicine. Then I started hurting on my right here [on his right side] and it just kept on. When it would hurt, I'd stretch and get my self together, and the next day or so, I'd do the same. That's the way it was. (59-year-old married Black man with colon cancer)

> My back had been bothering me off and on, 'cause I love to move furniture. So I didn't know whether it hurt 'cause of something else, or 'cause I had been moving furniture. I didn't think it was a problem and that's why I didn't check it out. I thought it was just from lifting or pushing and pulling. I told myself, my back hurt, go on with it. I never dreamed I'd have cancer. I didn't have no idea. (72-year-old divorced White woman with metastasized lung cancer)

For many patients without a family history of cancer, the thought of cancer never crosses their minds. Because beliefs and attitudes about susceptibility to illness play a major role in how symptoms are interpreted, the absence of cancer in the family tree makes it more difficult for patients to consider it as a possibility when they are seeking explanations for their ailments.

> I was spitting up blood and that wasn't right. And I had a funny feeling up here in my chest. I didn't want to go to the hospital, but my wife insisted that I go. The doctor ran some tests, and he had me taking the medicine. I didn't know what it would turn out to be, but when they found something in my lung, I knew I was in trouble, sure enough but I didn't have no idea I had cancer. That was not one of the possible things I was thinking about. There has never been no cancer in our family. My mother has had 3 or 4 heart attacks, and my brother had a stroke, but that's it. (48-year-old married White man with lung cancer)

> I found a lump in my breast right over here. I told myself, I said it was just a little cyst. I was going to check it out, you know, just for the record. That's all it was, just a little cyst. I never thought of myself as being ill. After about a month, after school begin, I decided to go through the motions of checking it out. I told myself I know its not cancer, I just knew it's not this. I never thought I would get it. I just never thought I would. Diabetes runs in the women in our family, cause my mother and my baby sister are diabetic. And its not funny but my baby sister says "you had to be different. All the others got diabetes and you had to go and get something else didn't you?" (54-year-old separated Black woman)

In spite of attempts to explain away the problem in benign ways, other patients report a long-time suspicion of the possibility of cancer and a growing awareness of its probability. While some patients come to this realization through an intuitive process, others use what they know about their health history and lifestyle habits to reach a logical conclusion about the source of their troubling symptoms.

> It was like things was going real good for me, and then I started getting a lot of pain around my stomach, and I had a lot of bleeding. This went on for 3 or 4 months. Sometimes at work, it would be like I couldn't just move. I would just pass out. I told them at work, if I tell you I have to go sit down, or I have to go lay down, then I had to cause if I didn't, I would pass out. And so, they believed me. It was like I already knew, I just felt like it was cancer when I first went in to the doctor before she started talking, and it was just like, I knew it was cancer. I just knew it was cancer. I just felt like it was. (46-year-old single Black woman)

> After my divorce, I started having seizures pretty regular and I came here and I seen a doctor downstairs for seizures, and he gave me medication. He was checking me out real good, and he listened to my lungs and didn't like the sound of it. I've been kinda smoking a lot of years, you know, auto mechanic and all that. I kinda figured that one day it would turn into cancer. So I been looking for it for years, smoking and all, being a mechanic and all. I knew it was coming one day. (43-year-old divorced White man with lung cancer)

> Well, the growth in my mouth had already been there, and I would feel it sometimes. It got bigger and bigger. When I would eat, it takes me about an hour just to eat. Even soda, it's real hard to swallow. You'd think that would be easy to go down cause it's not solid or anything. But I knew if it was swoll up on the outside, swoll up on the inside that meant they was closing off my passages like my breathing passages. At first I think it might be, uh, what's that, uh, it had to do with the strep throat, but the second one after that, I hate to say it, but I thought I might have cancer. It's time when it's this way, you better go and see a doctor before they have to cut your face off. (50-year-old single Black man with mouth cancer)

Delaying Diagnosis

Institutional barriers. The institutional barriers to health care for the poor are numerous and well documented (Abraham 1993). Prominent among them is the absence of private health insurance and the inadequacy or inaccessibility of publically funded programs. Respondents who are medically uninsured or under insured tend to approach symptoms with a "wait and see" attitude.

> I had this lump in my breast that I was watching for about a year to see if it would go away. I was waiting to see what would happen. It wasn't causing me no pain and I didn't have no insurance. Then about 6 months ago, that's when I begin to feel not like me. I would just feel like one of those days you don't feel good all over but and you're not knowing why. I was just blah. I ain't never been one to

> be like laying down though. (54-year-old Black divorced woman with breast cancer)

> I was having some trouble breathing, but I figured I could keep an eye on it to see if it was getting worse. I didn't have any kind of insurance or, uh, a job. I knew about this hospital and I knew I could come here, but I already owed some medical bills and stuff and I didn't know if I could get the insurance card with the previously owed medical bills. (42-year-old divorced White man with lung cancer)

The uninsured status of some patients is a source of stigma that keeps them from seeking care from private hospitals or accepting care in a charity hospital. As Kiefer (2000, p. 21) notes, in addition to all the other ways poverty affects relationships between patients and health care providers, "being poor makes many people feel vulnerable, help-less and inferior in many situations, and seeking care is often one of those situations."

> I never did like to go to doctors here. It wasn't that I was worrying about paying the doctor or something like that cause I had my medical card, but I've always been against this hospital, you know. It's a matter of pride with me. I never did like charity. It was the pain that finally got me to go to the emergency room, and that's where they told me I had a bad appendix. They had to remove it. When I was going through the process of the operation, they traced the problem or whatever, and that's when they found I had cancer in my colon. And now it's in my liver. I only got two spots on it, but that's, that's a possibility of being incurable. (59-year-old married Black man with colon and liver cancer)

> It's like I said, I didn't have any insurance, and when you ain't got no insurance, uh, you go money, you go to the doctors, they, see you but they don't treat you, you know, and that's one of the saddest things there is. If you go to the doctor, they'll see you, but they don't treat you like a person that got insurance. Understand what I'm saying? And you go to a emergency room, first thing they do is ask you what kind of insurance you got. If you say, "none," that's written down there, and you can sit there or lay there and look at everybody that come by and pick up that chart and they say, [in a whisper] "well, she ain't got no insurance. No insurance." You understand? I'm telling you. I'm saying that they don't be intending you to hear 'em. But you listen so, you know. I can hear, and plus I can see. If you don't have insurance, okay, they give you a certain amount of service, and they bill you for it, yes, but it's not the same. That's why I didn't go. (54-year-old divorced Black woman with common-law husband)

Among the poor, mistrust of the system combined with concerns about the quality of the diagnostic procedures and the treatment protocols serve as a lens through which they evaluate encounters with health care providers and make decisions about seeking care. Retrospective accounts of the events surrounding their cancer diagnosis reveal that even before the diagnosis, patients put little faith in the capacity of the system to work for them.

> To be honest with you, I'm not a big fan of hospitals and doctors. It might just be me, but it seems like they can't ever figure out what they're doing. That's why I waited so long to get this checked out. This last time, I spent a week here in the hospital while they was running tests and stuff. Then they transferred me from here to the research hospital because my left lung had collapsed. They had to do surgery to re-inflate the lung and that's when they found it. Then two days after Christmas they told me I had lung cancer and bone cancer. The doctor was more surprised than I was. He said that they didn't really expect to find that, but they did. I had come to the emergency room and had fluid my lungs, and they were trying to find out what was causing that, but I really wondered if they would have tested for the cancer if my lung hadn't collapsed. I could be dead, and they could still be trying to figure it out. (42-year-old divorced White man with lung cancer)

> I hate to say anything bad about anything, but there's is definitely something not right with the kind of care poor people get. I had these indentations on my breast and they would do like that. They were just there on your side and under my arm-pit. There was right here, on my breast, under my breast. It was here, and I could just see that thing, and then it was warm to the touch and it was kind of reddish looking. I didn't go to the doctor right away, because I didn't want to have to go through all the hassles of dealing with them. Then back in November I went and had one of those free mammograms, and that didn't show anything. When they didn't go away, I came back to the clinic, and I had 8 mammograms in one day. I asked the doctor why they didn't show up the first time, and he said that sometimes when people get older, their skin toughen up, and I said, "un huh" [shaking her head in disbelief]. I don't know why I ever believed what they told me. I never trusted them from the start. I was just hoping it was nothing and wanted to believe it even though I knew better. (51-year-old divorced Black woman)

Although some patients do not delay seeking help with a health problem, it can take months of doctor visits and misdiagnoses before they actually find out they have cancer. In the process, patients are often shuffled from one doctor or hospital to another in a process that reinforces the negative stereotypes the poor have about the health care system.

> When I got sick, you know, I was in the other hospital. They put these machines on me, and they run a whole lot of tests on me. He and the other doctors said it wasn't no cancer or anything, nothing like that. See, what I think it was, he didn't want to treat me. So he said he didn't know what to give me, and he sent me over here. They was the ones that told me I got leukemia. (67-year-old divorced Black man with leukemia)

> I couldn't hardly swallow anything. When it got real, real bad, I couldn't even swallow Jell-O. But I was still going to work every day, because they had told me that I had bronchitis, and they gave me a bunch of antibiotics, and it didn't get better. It was getting worse, and I kept on going back to the doctors. I could never get a straight answer out of them about why I wasn't getting better. It was like they didn't have time to find out what was really wrong with me. Finally I went to the emergency room and told them that they had to so something about my bronchitis, and that's when I found out I had Hodgkins disease. (34-year-old divorced White woman with Hodgkins lymphoma)

Failure to seek health care in a timely fashion, however, often has as much to do with the presence of certain personal coping strategies among the poor as it does with the existence of institutional barriers to care. Because it jeopardizes employment status and cuts off the flow of reliable income, capitulation to serious illness is rarely an option for most of the patients. Without doubt, lack of adequate insurance is a barrier to health, but income and insurance status alone cannot explain the illness behaviors of the poor. To get a more complete picture, however, we need to consider how the demands of a poverty lifestyle produce attitudes toward time and pain that discourage patients from attending to the physical signs of disease.

The constraints of time. The notion of time as a resource (see Yoels & Clair, 1994) is salient for respondents as they attempt to find enough hours in a day to sustain life as they know it. As one patient put it, "I had things to do. I had no time for this. I had no time to be sick" (54-year-old Black woman). Because time is a limited resource, sickness is a luxury that the poor cannot afford. As another patient recalls, "I put time before my health. I should have put health in front of time instead of thinking I ain't got time now, I don't have the money" (50-year-old Black man with throat cancer). Over and over again, patients express a sense of being overwhelmed by the demands of a life in which there is no time to be sick, and for many of them, in which the health of other family members takes precedence in the hierarchy of demands that fill their daily lives.

> I was feeling weird, you know, feeling bad. I was tired and I was under a lot of stress, but who has the time or the money to go see the doctor just for stress? My mother was running me to death all the time, you know, wanting me over there all the time. And I just couldn't say no to her, you know. And my husband, he was, he wasn't feeling well. He's got diabetes and severe hypertension, and he's had four bypasses done. So mother she was putting the stress on me, you know, cause she won't eat unless I'm there. When my husband was sick, she got dehydrated and got in the hospital from not eating, cause I couldn't take the time to watch her eat. Then I got one daughter that's living at home that I look after. She's got a mental problem. Now she's got Medicaid and he's got Medicare, but I don't got nothing, and I got all these people needing me. (57-year-old remarried White woman with colon cancer)

> I would feel it, you know, there was a knot in my breast. I noticed it before the pain, but I didn't do anything about it. I did worry about it, but I thought maybe it's just something, you know, because I could move it. I was supposed to have a mammogram in '99, but mother had her colon surgery that year. I mean she had an operation the same morning that I was supposed to come over here. But, like I said, I could feel it in here. It was hurting, pulling like I'm pulling, you know, like I'm pulling on a fan or a mobile or something. When it got really painful, that's when I told my medical doctor, and he made me the appointment for the mammogram. (53-year-old divorced Black woman with breast cancer)

For the poor, making ends meet is often a juggling act in which dropping the ball to attend to things which do not directly contribute to day-to-day maintenance of life is out of the question. Because life is a struggle and things don't always work out the way they should, physical problems do not necessitate an urgent response from the poor. For most patients this translates into years and years of less than optimum health status.

> I should have had a hysterectomy a long time ago. Well, [sigh] it was about 8 years ago, I had a IUD. I don't know if you know about 'em or not. So anyway, I took it out 8 years ago, and that's when they told me, they said, well we got to in and do a complete hysterectomy. Well, I didn't want it, so I put it off. At the

> time, I was working, trying to keep my house together and everything, and so I didn't have time. Now I know I should have took time. (53-year-old divorced White woman with cervical cancer)

> I went for a physical and the doctor found at a tumor about the size of an egg in my stomach, and he had told me that I had to have it smelted off. But I didn't know when I was going to be able to do it and then I didn't do it. That was 20 years ago. The doctor had his nurse make the arrangements, but I just wouldn't go. When I finally got to the doctor, it took them a while with all the tests to find out what was wrong. They finally said I had tumors in my uterus and vagina. It was during that time they found the breast cancer too. The surgery should have been in March, but they had to reschedule it for June because I was in the process of losing my home, and I needed to find a place to put my stuff. I'm still not all that settled yet. (49-year-old single Black woman)

> It started years ago with the growth on the roof [of his mouth]. I still remember how there use to be a dentist upstairs and my mother use to take me to get my tooth pulled when I had a bad tooth. He told me there was a growth up there and that we needed to get it removed, but I told my mother, but mama said, "it ain't been doing nothing." And, you know, mama got three kids to take care of and they ain't got any sense bothering with it, to take it out or something like this. Once, this was about 10 years ago, I went down here to the eye, ear and throat clinic, and they took a little sample of it, and told me "we want to put you in the hospital." I never did go back, cause at the time I couldn't afford to take time from work, you know, and it wasn't doing anything, so I figured why should I go it debt to go to the hospital. (50-year-old single Black man with mouth cancer)

Perceptions of pain. The pressure of time constraints interacts with the absence of other resources such as money, medical insurance, and housing to affect the patients' interpretations of the seriousness of the symptoms and their perceptions of the urgency of treatment. There is a range of tolerable discomfort in which the poor operate, and only when the pain of illness and the frustration of disability become intolerable do they turn to the health care system for help. Delaying diagnosis can be attributed to the tendency among the poor to gauge the severity of symptoms by the intensity of pain. In palliative medicine, pain is the fifth vital sign routinely checked as part of an ongoing assessment of patients' conditions. Controlling, minimizing or eliminating pain is a desired goal for patients and health care providers during the palliative phase of care for the terminally ill. In the prediagnostic and treatment phases, however, the absence of pain is misleading for patients who perceive pain as the most significant symptom of serious illness.

> I was sick, and didn't know I was sick. I didn't know where the problem was because nothing hurt. I was, I was getting tired easy, shortness of breath like I couldn't carry a bag of groceries from here to that building there across the street. I'd given out. I let it go on for three, four, maybe five months till I go the doctor to see what is wrong with me. I say, I can't take it no more, and I came over here. They put me in the hospital that day, and the man told me if I hadn't came in, I'd a died. It was just tiredness and just things that I felt I, I was able to do, cut grass and do this do that, I just couldn't do it. I couldn't even carry a bag of groceries without having to sit down and see, you know, what's happening. I didn't know what was wrong. I just thought I was just tired, cause I never did have no pain, and I didn't know there was anything wrong. (54-year-old divorced Black man with leukemia)

> I had a little bitty small little knot right here [pointing to her left breast], a little bitty small little, it was like a pin hole. It didn't give me no pain. It wasn't really bothering me, and I fiddled around with it for 6 months or so. I knew something was wrong though, 'cause it kept discharging. I didn't know what it was, and until it started pressing on my rib cage, I didn't do nothing about it. That's when I, you know, went downstairs to see the doctor. It was just, you know, when it started hurting and bothering me, that's when I went to try and find out what it was, because, you know, it was just pressing on my rib cage. It was a painful pressure feeling. (53-year-old common-law Black woman with breast cancer)

Because the prediagnosis behavior of patients has such important implications for the efficacy of treatment protocols, health care providers and policy makers need to attend more systematically to the context of meaning that frames patients' interpretations of symptoms. Among the respondents, for example, there is a tendency to embrace the notion that hardship makes a person stronger and more capable of carrying on in the face of adversity. As part of a larger belief system that values hardiness, vitality, and quick wittedness, "there is pride for many poor in their ability to endure . . . and steer their way nimbly through a chaotic life" (Kiefer, 2000, p. 42). Because this inclination promotes an image of self capable of outwitting hardship by withstanding discomfort, it often leads patients to ignore all but the most unbearable pain.

> I've always been very physically strong and basically able to withstand pain. I felt like I was strong as an ox. I never like to go to doctors and like I said. I was never one of 'em to cry and complain about every little ache and pain. Like I say, I would just go about my business and make the best of it. But it got to where even I couldn't take it anymore, [waving his arm] and I had to go. It was the pain, you know. I'm talking about pain like I ain't never seen before. (59-year-old Black man with colon cancer)

> The hardest part for me was admitting that I was really that sick, you know. I'm not the sickly type and I don't like having limits on what I do. I always believed that even if a person didn't feel good, they should make themselves get up and be active and keep themselves as strong as they can and as mobile as they can. There's more than one way to deal with sickness. But this time it was just the pain that caught me off guard. The pain got to be just too much for me. (42-year-old divorced White man with lung cancer)

Immediate Responses to the Diagnosis

Self in Crisis

For individuals attempting to cope with the diagnosis of an incurable illness, the crisis of self unfolds on physical, emotional, social, and spiritual levels as patients try to hold on to life as they have known it. As Cassell (1991, pp. 33 & 36) explains,

> suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some manner. . . . In these situations, persons perceive pain as a threat to their continued existence— not merely to their lives but their integrity as persons.

In this respect, the terminally ill face many of the same challenges of identity preservation as their chronically ill counterparts. Over time many patients report a "loss of self" and an inability to reconnect with the person they once were.

> Somebody told me once a long time ago I was a free spirit. I often wonder how I have changed personality wise and character wise and all, 'cause I don't realize

> how I used to be before I got sick. Now I wonder how, or if it has changed me. (34-year-old divorced White woman with Hodgkins lymphoma)

The multidimensional nature of the terminal illness crisis is not always articulated by patients, however, because they experience it as a global assault on the integrity of their personhood rather than as a set of discrete problems to be managed. As one patient put it, "I felt like I would never be like I used to, that was about the only thing. It was not any one thing, it was the whole thing." This inability to compartmentalize effects of the diagnosis contributes to the shock and turmoil that typically accompany a terminal diagnosis.

> I've never been more surprised in my life, in all my life. I didn't see it coming. I thought people got cancer who smoked. I just never suspected. I was scared to death. It was just unreal. I knew my life would never be the same again, but I wanted to know how long I had to live or if there was a chance of me living. (48-year-old married White man with lung cancer)

> When they told me, all I could think about was that I wouldn't be normal any more. It was a hurting feeling, a hurting feeling. I didn't feel like I would ever be normal again. A lot changed when I heard the word cancer. You know, I mean, just the word [cancer], it's not normal. I was afraid that a lot was going [to be] taken away from me with an illness that's . . . an incurable illness. I tried to focus on my body and taking care of the worries of the disease. I didn't want to think about heavy things. But deep down, I knew that it was more than that. I knew that the disease was eating away my insides. (54-year-old widowed Black woman with colon cancer)

Existential suffering. The existential crisis that accompanies a cancer diagnosis is not peculiar to the poor. For individuals of all social classes, suffering in the course of terminal cancer transcends the physiological manifestations of malignancy to incorporate spiritual and psychosocial issues as well (Rousseau, 2001, p. 371). For the terminally ill, it is not uncommon to fear death and worry about loved ones left behind. As persons face death, they typically review their life and experience remorse for personal failures and shortcomings. In those respects, responses of the terminally ill poor to death differ little from the reactions of the more affluent or better educated.

> I felt bad 'cause they're telling me I got leukemia, and you know, leukemia will kill ya. They saying there's not a cure for it. I don't like having it cause I know it's a deadly disease. I thought about it, you know, and I just thought about it, and it made me sad to think about dying and missing my grandchildren. It stayed on my mind for, you know, for a pretty good while. I was worried about it about 5 or 6 months or something like that, worried about how long I'm going to live. I really want to live a little longer. I want to live long enough for my grandchildren to get big enough that they won't forget about their granddaddy. I want them to remember the good things I used to do. I did some things, and I know they was wrong. I wouldn't do them anymore if I had the chance to live. (67-year-old divorced Black man with leukemia)

> The first thing I said is "am I going to die?" I've been in and out of remission a lot, and each time feels almost as scary as the first. I really don't like to think about dying. I have a teenage son that needs me and a boy friend that loves me. I feel like I shouldn't be dying. My life hasn't been easy and some of it wasn't my fault. My parents were deaf and my mother just left me and my dad, and my dad couldn't raise me alone with him being deaf and everything. So I was four when I started living with my grand mother, and so she adopted me. She had arthritis real bad and couldn't keep the yard up and everything. So she had to get a yard man. One day he come in and, uh, beat her up with a stick, robbed her and killed her. I felt like I should have been there to help her, [tears] but I was here when it happened. I don't think I'll ever get over it. (34-year-old divorced White woman with Hodgkins lymphoma)

The crisis of self which unfolds for the poor, however, is unique because of the relatively young age of patients at the time of diagnosis. Cancer diagnoses that typically occur in the 50- to 70-year age range for the larger population commonly occur during the 40- to 60-year age range among the poor. Although "dying young" is a relative concept related in many ways to class- and race-related expectations of longevity, for the poor the fear of dying young is especially pronounced when it revolves around thoughts of leaving behind dependent children whose well-being could be in jeopardy.

> Finding out was the worst. I was in shock and couldn't stop crying when they told me. I thought about how far it had spread and what stage it was in. This was a young life we were talking about. I didn't want to die young. I was scared that the cancer would go somewhere else, and would have to spend the rest of my life

> getting ready to die. I always dreamed of living to old age and seeing my kids graduate, grown, married with kids of their own. I knew they would remember me as a loving mother, but still. It was real stressful on my daughter cause she told me when we found out that she didn't want to go live with her daddy. More or less, her daddy's disowned her. I didn't even tell my ex-husband. He still don't know. And he won't know because he's the type to try to make it bigger than it is and try to get custody of the kids. (37-year-old divorced White woman with breast cancer)

> When they told me, it shocked me, you know, and I started to cry. I thought I was too young to die, and why did I, you know, have to live with this because of my kids [tears]. I didn't want nobody else to take are of my children. My little girl, she's got cerebral palsy and it takes a lot to work with her. Nobody else could give her what I give her. And my boys, they need their mama, too, so they don't turn bad. It was difficult at first, you know, after they told me I got cancer and I thinking I got to live the rest of my life with cancer over my head. It got to where I would wake up at night crying about it. (23 year old single Black woman with lymphoma)

As they face death, the poor also suffer because of an inability to control their destiny. Among those who observe the poor, what is often perceived as a passive acceptance of fate, magical thinking, and an external attribution of agency instead may be the product of a volitional process consistently thwarted by lack of resources and the constraints of the larger society. Individuals' hopes for a better life may remained unfulfilled because of structural barriers to education, employment, and health care. Fear of dying young and not experiencing life to its fullest is especially poignant for the poor, because their life circumstances have not afforded them opportunities to fulfill their dreams.

> I don't know if she was a doctor or if she was training to be a doctor, but it was blunt how she told me it was cervical cancer. It was almost like she thought if she was easy on me or something, I would just fall apart and give up or something like that. I wasn't going to even if she did. I cried, but I never, I can't say I got depressed because I didn't. But I think the most thing that I got depressed about was how was I going to live. It's hard enough to keep going when you're well. Of course I wished I didn't have it. I didn't want to die. I wanted to be around just to be around. I didn't want less of life. I wished there was more of it. I haven't had enough yet. I always wanted to go to San Francisco. I'm still trying, but I don't know if I'll ever go. I told my daughter, when I died, I told her that I wanted to be cremated and I wanted her to take my ashes to San Francisco. (46-year-old single Black woman with cervical cancer)

> They told me the treatments would be difficult, but I was willing to try this and that and whatever. But you just never know if anything you do will do any good. I was frightened, cause I knew it was on me to do something. But I felt like there was nothing I could do. The biggest problem was my kids, you know, how to tell them. I knew they didn't want me to have it, but I just couldn't help it, you know, I didn't want it either. I wished I didn't have it. I was scared that it could get worse, and nothing we tried would work. I started wondering what it'd be like to die, but I wanted to live for my kids. I wanted to take them places we've never seen. We'd always talked jokingly about going on a cruise someday. (43-year-old divorced White man with lung cancer)

Attachment to material things is also a source of suffering for the terminally ill poor as they find themselves losing grip on the very things that have marked the meager successes of their relatively short lives. Perhaps this irony can be understood in light of Rubin's (1976, pp. 17, 206) insight into the symbolic importance of home ownership and consumption for the working poor. "When a family has worked so hard, waited so long to acquire these goods, they are not treated lightly . . . [and] each new purchase was an affirmation of self and a confirmation of their well-being, of their status — a statement to the world that they were doing okay." As awareness of personal mortality replaces more mundane concerns in the minds of the patients, the physical evidence validating their life achievements become more significant.

> My house is my achievement. It ain't no mansion, but it's mine. I'm particular with what I got. I guess because I worked and I got everything I got with my two hands on my own. I never wanted for nothing, 'cause, though I never wanted much, I always got what I wanted. So that makes a difference with a person and it depends on what a person wants, what kind of life they want. After I'm gone, I hope they take care of this place. I want it to be clean and not trashy. I just look at some people and how they're living and I don't want that to happen here. It makes me sad to think that when I'm dead and buried, everything I worked so hard for all these years won't be worth a hill of beans. (72-year-old divorced White woman with lung cancer)

> I love to keep my little house up. I mop the floor, wax it, and I take my blower and blow off the back of the yard to keep it looking good. I've been in that house for 21 years and I got 9 more years before it's paid for and all mine. I worked all these years and, and I really tried to hold on to it, to get it paid off. I'm not seeking out for a whole lot from life, out of life, you know, like a lot of whole brand

> new cars, and all that kind of stuff. If I can just basically hold on to what I got. My son's been asking me about my tools. I got a lot of tools through the years. I know I can't take 'em with me, but I'm not ready to part with them. Down the road I still would like for him to have them rather than anybody else, but right now they're still part of me. (59-year-old Black man with colon cancer)

A landscape of despair and death. For many, the existential crisis accompanying a cancer diagnosis is intensified by personal acquaintance with the cancer trajectories of others in the family or neighborhood. As an illness that rarely goes unnoticed among the poor, a cancer diagnosis carries with it a "cultural salience" in contemporary society that is particularly troubling to the poor. As Kleinman (1988) notes,

> Cancer is an unsettling reminder of the obdurate grain of unpredictability and uncertainty and injustice in the human condition. Cancer forces us to confront our lack of control over our own or other's death. Cancer points up our failure to explain and master much in our world. Perhaps most fundamentally, cancer symbolizes our need to make moral sense of "Why me?" that scientific explanations cannot provide. (pp. 20-21)

Perhaps better than anyone else, the poor are cognizant of what can happen to a person's life when cancer intrudes, so they are especially vigilant in marking its presence among them. As one patient explains, "with the 'big C,' it would cross anybody's mind, cause you're bound to associate living with cancer with death" (50-year-old single Black man with mouth cancer). In their midst, cancer generates a complex mixture of overwhelming fear of their personal vulnerability and heartfelt compassion for the plight of the victim.

> We had a neighbor girl, it was just like that, and she was real young. She hadn't been too long passed away, but she suffered with cancer real bad. We knew her real well, and she left two little boys. It was so sad. It had started from her neck and it went all over her body. I think she was about 24-years-old. She died at home with her mother. (53-year-old divorced Black woman with breast cancer)

> Mother died of stomach cancer a long time ago. When it got bad, she wouldn't eat or nothing, you see, and it put me through hell to watch her die. I was the one

> that took care of her when she couldn't do for herself. (67-year-old divorced Black man with leukemia)

Because the poor have some of the highest morbidity and mortality rates for most major types of cancer, there is a greater likelihood that those living in poverty will have had multiple exposure to the ravages of terminal cancer. In this study, it is not all that uncommon for patients to describe family health histories in which more than one family member has died of cancer. As one patient describes it, in families where cancer is prevalent, the word "cancer" carries such powerful connotations that it can function as a synonym for other deadly illness. "My aunt had cancer, her oldest daughter had cancer, then my mother, I just consider it cancer, 'cause diabetes is a bad disease if you don't treat it right" (69-year-old married Black woman with breast cancer). For these patients, there is little comfort in the thought that their suffering and death is part of a legacy of family misfortune.

> They brought me up here to the emergency room. They just started running tests on me and everything, and started giving me fluids for dehydration. And after they'd runned the tests, within two hours they knew what was wrong with me. They told me that I had cervical cancer. The thought went through my head, my dad had died with cancer and my, my ex-mother-in-law, she had died of cancer and all, and I thought well, this is me, too, I'm going too. (53-year-old divorced White woman with cervical cancer)
>
> My mother died of breast cancer at 52. When they took my mom's breast off, she just didn't want to live, cause they did a bad job back then. They just butchered her, and she was a pretty lady so she just didn't want to live. So we kind of watched her just fall under, you know. My oldest daughter had breast cancer at 35 which was 5-years ago. My sister died of breast cancer 2-years ago. And now me, so it's been a long line of cancer in our family. I used to think it wouldn't come as a surprise if it happened to me and in a way it didn't. But in a way it made it worse because of what I've seen all of them going through. (63-year-old divorced Black woman with breast cancer)

Dealing With Others

The existential suffering accompanying a terminal diagnosis becomes even more complicated as the realization of an unfolding crisis expands beyond the awareness of the patient and enters into the collective consciousness of family, friends, and acquaintances. The social nature of a cancer diagnosis carries with it an unwritten expectation that others will be part of the process. As one patient put it, "cancer always involves somebody else, and once you've exposed family members to whatever's happened to you, you're no more in charge" (63-year-old divorced Black woman with breast cancer). When this happens, patients assume the added burden of anticipating others' reactions and interpreting the social implications of terminal illness.

Anticipating others' reactions. The ability of patients to imagine how others will respond to their cancer diagnosis is a double-edged sword. On one hand, the anticipation of others' reactions does afford patients the opportunity to prepare for them. As a patient explains, "the word cancer scares people, it scares people to death so, I had to figure out some way to keep that from happening" (53-year-old divorced White woman with cancer of the cervix). On the other hand, preoccupation with the anticipated responses of others can erode an already diminishing supply of psychic energy.

> I got tired of trying to think of what I would say when they ask me how I am. I know they just wanted to know how I was feeling, but I'm always going to have it, there's no cure for it. I decided I'd just say when they ask, the answer I would tell them is "Oh, I'm hanging in there." And they would say, "Well that's good, you know." There's not much more a person can ask after that, so I figured they would just hush. (34-year-old White woman with Hodgkins lymphoma)

> I really didn't want everybody to know. People that don't know me, you know, just people that I knew in general, don't need to know about me. It's a personal kind of cancer that don't need to be talked about or speculated about. I don't have no idea what caused it. I had always told my children, I was going to live to

> my old age, and I told them if I ever caught cancer it would be throat cancer cause I smoke. So I don't see why I had to get cervical cancer, but you never know. I wasn't ugly to people or nothing, you know, but I didn't want them asking me a lot of questions. (46-year-old single Black woman with breast cancer)

Anticipating the disapproval of others, many patients feel it is their responsibility to maintain social harmony and insure that social encounters do not generate negative responses from others. Fear of disappointing or displeasing others motivates patients to modify their behavior in response to the perceived expectations of others.

> I've always tried to do things the way my daddy did them, cause he kind of set in his ways and nothing's going to change his mind. When they found out I had the bone cancer, they told me, that it was up to me whether I even took chemo. So I decided to take the chemotherapy. My daddy took it when he had lung cancer and now he, you know, his is in total remission. He don't have any tumors showing or anything, and he seems to be doing just fine. So I figure even if there was with the bone, with the bone cancer, even if there's not a cure, that, you know, I ought to do everything I could to, to get as well as I could. Daddy always been one that don't believe in taking a lot of pills or anything and I knew he would get on my case about it. Sometimes when he's at the house, my medication will make me nod in and out. He wants me to quit taking it, or he feels like I might be taking too much of it. When's he's around I try not to take so many so I don't get him started. (42-year-old separated White man with lung cancer)

> Some folks are very insensitive about cancer. I've seen them talking about people they know with cancer and saying they wish they wouldn't be carrying on and crying so much. So I didn't want to act like that. I didn't want to hear them talking like that about me that way. (72-year-old White woman with lung cancer)

Because the responses of others shape the way patients feel about themselves, subjects express concern about the effect that the emotional responses of others will have on their capacity to cope with terminal illness. Familiarity with the emotional dynamics of family and friendship groups leads patients to anticipate an onslaught of paternalism and pity.

> I didn't tell everybody, you know, I just told close family. I guess I didn't want everybody to know. I thought they would feel sorry for me, and I didn't want anyone feeling sorry for me. I wanted to be treated just like before, no different. I just told the ones that I thought would be with me through it, you know. (54-year-old separated Black woman with breast cancer)

> I didn't want to tell anyone about the cancer, but I had to tell the important ones, the ones that look after me. I just knew my sister and daughter would be scared, and I didn't want to frighten them. I didn't go out and try to broadcast it. Just going out and just one ear to the other, no I didn't do that. I didn't want no one feeling sorry, you know, or mopping or whining and all of that. (42-year-old single Black woman with breast cancer)

The social nature of cancer can be typified in the responses of recreational and church groups to the cancer diagnosis of one of their members. While such groups can be a source of social support, the anticipation of community intrusion can be an occasion of stress for patients.

> If I tell them, they'll make too big of a fuss about it. They asking around without making a big fuss it, about, oh, you know, they found out he's got cancer, they be saying, you know, "let's do this, let's do this, boy, you just don't know, Lord, he got it." Just get it out. If they don't know, they won't have to go through that. Just leave me alone. I won't be no problem. It's just like the first couple of days I was here, the first day that I missed bowling, and everybody was so upset I was in the hospital, folks were asking where I was, and they didn't know, and everybody was asking about me. And they were asking mother, they were calling her house trying to find out, and she wasn't going to tell them cause of the fact I told her, I told her "tell them you don't know, just tell 'em. Just tell 'em you don't know." (50-year-old single Black man with mouth cancer)

> My preacher called us up one Sunday and said "anybody whose got a sickness, come and whisper it in my ear, and I'm going to pray for you." I don't have to come and, to me, I don't have to come and whisper my sickness into your ear. I can whisper my sickness and God will hear and pray to God for myself. I can push for my sickness and tell God to tell Rev. Jones to pray for me. But I didn't go up there, because that's, that's not the way I want to do it. First of all, I was on the sick list, and he didn't bother to come and see why I was sick then. So why should I come up there now and whisper in your ear? I though that was so weird. And then, too the microphone was halfway on, you could hear what some people were saying. I didn't want the whole church to know I'm sick or what's wrong with me. (46-year-old Black woman with breast cancer)

Interpreting the social implications of terminal illness. More than anything else, the patients look for confirmation of their ongoing status in the ways others respond to them. Cooley's (1902) theory of the "looking-glass self" explains how the individual's sense of self is mirrored and reflected through others. As Marshall (1996) explains,

> The looking-glass self highlights the ways in which an individual's sense of self is derived form the perceptions of others. Just like the reflections in a mirror, the self depends on the perceived responses of others. . . . The looking-glass self has three components: the imagination of our appearance to the other person; the imagination of their judgment of that appearance; and self feelings, such as pride. (p. 296)

In the process of affirming their personal and social continuity though the eyes of others, patients find that they must be selective in their choice of mirrors, because not everyone is capable of looking beyond the signs of illness to see the social viability of the person who remains. As one patient recalls, "I had a friend, and when she found out I had cancer, she told me, she couldn't deal with it." By associating with others whom they believe will respond favorably, patients up the odds that the view of self reflected to them will correspond with the self they know themselves to be. When patients receive the feedback they seek, it becomes a source of personal gratification to know that others' perceptions of them have not changed. This, in turn, enables them to engage their social worlds from a position of equality.

> When I first called people, I told them first, before I told them anything else, I told them, I'm not going to die. And then after I told them I had cancer. I try to still be myself when I'm out and everybody that sees me, says you're still the same. They tell me that, and I feel good when I hear it. It helps me to keep on going. (46-year-old single Black woman with breast cancer)

> I always loved automobiles, cleaning up my car, and stuff of that nature, you know. I appreciate, uh, I have friends, this special one, he has his own mechanics shop, and I go there and I sit there and I watch him do something, and he if needs a wrench or something, I hand it to him, or give him a bolt. He says you've got to put your hand on something. It makes me feel normal, you know, to think he thinks I can still help out and be part of it. (59-year-old married Black man with colon cancer).

For some patients the struggle to come to terms with their terminal illness is more difficult when the affirmation of others does not come across as sincere or helpful.

> I haven't had enough time to do a self-inventory and get better knowledge of my own condition. I've had people say, you don't look like you got cancer. I don't know how people look with cancer unless they have that phased out look, but that's with the kind of suffering or the hair loss, but other than that, uh, I look the same. But, I haven't connected with how you look to how you feel, yet, with what you got. I still get a lot of sympathy from friends and associates which I'm not used to. I've had the comment, I can't stand to see you sick. You can't stand to see me sick? I'm sick, and I have to live with it. I don't think people with cancer should be treated any different. It's just some that need more attention than others. (63-year-old divorced Black woman)

For many of the patients, awareness of terminality goes hand in hand with fears of social death. As a concept, "social death" has taken on a variety of connotations since Sudnow (1967) first observed the way nurses in hospital settings disengage from dying patients. Today it is generally understood in its broadest sense to mean "an absence of behaviors we would expect to be directed toward a living person" (Kastenbaum, 1998, p. 4). In the lives of the terminally ill poor, fear of social death often involves awareness of the stigmatizing and isolating potential of cancer.

> I told my daughter right away, and she was sad when I told her. After I told my sister and brother, I think they felt sorry for me. There was no way I could keep it from them even though I knew they get all over me with it. There's lots of people in the general public that still don't know, cause I never did tell them. I just don't jump up and tell them what kind of disease do I have, you know. I don't do that. It ain't none of their business. There ain't nothing they can do for me, and some people get scared of it though, cause they figure they're going to catch it from me. But you just can't catch that stuff from nobody else (67-year-old divorced Black man with leukemia).

> Now I shared it with my kids, but even more with the nurses and the staff here. See, they encourage me to. I didn't try to hide it, because I had it but, basically I shared it more since I've been coming here taking treatments than I did to even my relatives. See they mind if you have it, but I hope they would treat me not as an invalid like it's something catching. Don't treat me like that. I'm just me, myself. I don't feel any different. I feel the same, I'm the same man. I try as hard as I can just not to pity myself because of my illness, and I don't want no one else laying pity on me. (59-year-old married Black man with colon cancer)

Among the terminally ill, social death can also refer to behaviors that indicate the loss of equality in social exchange. When this occurs, patients are no longer addressed as subjects whose social position is intact. Instead, they are treated as objects whose social attributes and personal boundaries are no longer relevant. It's as if their lives no long longer belong to them.

> I've seen them do it before, and I've probably been guilty of it myself. It's this thing that people do that makes you feel like you're not really there. Like, one of mother's friends got a friend that's had cancer for the last years, and he just died a week ago. When they was talking about the funeral, it was like they didn't know that it might bother me to hear about all that stuff. You know, them talking about the funeral and just other things like that when they know I'm probably going to be next, it gets to me. (42-year-old divorced White man with lung cancer)

> I only told family, and people at work the first time. I didn't want people's pity, and I didn't want people looking at me like I was already dead. I was shocked when the word got out about my recurrence, and people thought I was going to die. I knew having cancer would make people treat me like my life was everybody's business. It's almost like them thinking I'm already in the coffin and they can come to the funeral home and look at me like I'm on display or something. One acquaintance from high school thought I was already dead. She called my sister and asked when the funeral was. People who hadn't kept in touch with me since high school were calling. I felt like they didn't keep in touch all these years, so why now? It was like all that mattered about me was the cancer. (46-year-old single Black woman with breast cancer)

In response to threats to the integrity of the self, patients devise ways to manage the illness experience over time. Although coping styles vary from person to person, certain themes take on a special salience as patients seek to restore coherence and negotiate for support. As they deal with the illness over time, patients look to the past for a sense of continuity and elicit help from others to sustain the cognitive and affective frames they need to support a pre-illness sense of self.

Dealing with the Illness Over Time

Although few things in life can compare with the terror of a terminal diagnosis, life rarely unfolds without disappointments, hardships, and losses. As we have seen, the flow of life events that precede a terminal cancer diagnosis are punctuated by occasional interruptions in the regular scheme of things and temporary exceptions to the rule of normalcy. Such disruptions in the continuity of life's course often carry with them a sense of personal vulnerability and social jeopardy as well as a desire to return to the status quo. With the diagnosis of a serious and recurring illness, however, the potential for personal disintegration and social fragmentation is heightened over time, and the impulse to restore normalcy is quickened. As Cassel (1991) notes,

> The relation of individuals and their actions to others and to the world are usually harmonious, rhythmic, and orderly.... Disorder, discord, and disharmony are painful experiences, and individuals go to considerable lengths to avoid them. The chronically ill person may be unavoidably out of harmony with his or her world and other persons.... The chronically ill person is also aware of the dis- discomfort arising from the disharmony. Unless the discomfort can be set aside, it can become an intolerable barrier between the ill person and the surrounding society, a source of suffering that remains until internal harmony is restored. (p. 55)

Among the poor, religious faith can be a powerful resource in mediating the stress of personal indignity and painful loss. Religious explanations for personal hardships can alleviate the sense of powerlessness that accompanies life crises. In the face of death, the spirituality of a religious impulse can provide the context of meaning, assuring personal significance and social continuity (Idler, 1995). While the existential crisis engendered by a terminal diagnosis typically revolves around thoughts of the afterlife, the human dilemma of making meaning in the face of death is also articulated in the vocabulary of the temporal and the mundane. For the terminally ill poor, the onset of cancer produces an initial shock whose duration depends on how quickly the patient can cushion the blow by adjusting their subjective perception of objective reality. Instead of redefining the self as a way of managing the new set of contingencies in their lives, respondents manipulate the temporal dimension of their lives in an attempt to restore a sense of pre-illness normalcy.

Normalization: Maintaining Earlier Selves

In many ways, the normalization process of the illness experience for terminally ill patients is indistinguishable from that of the chronically ill. In her examination of the temporal dimension of the lives of the chronically ill, Charmaz (1991) found that persons try to focus on the present, living one day at a time and marking the passage of time in comparative terms. Good days stand out because of the refuge they provide from the disabling symptoms of chronic disease. Bad days, on the other hand, recur with dreaded frequency and blend in to the long process of losing oneself to the illness. In his research on suffering in chronic illness, Cassell (1991, p. 50) finds many patients are "living entirely in the present, because suffering requires anticipating a feared future." During the treatment phase of incurable cancer, patients often employ the language of chronic illness to recount the day-to-day struggle with declining health. Like their chronically ill counterparts, the terminally ill report the use of coping strategies that involve focusing on the present and taking one day at a time. In this way, the passage of time is mentally recorded in manageable segments that do not overwhelm the patient.

> Right now, I'm not thinking about the future. See right now, I'm gearing up to 3 months tops. I'm not thinking beyond that. From what they're telling me, I'm going to have to be taking these treatments for that long. It'll be 3 months of this and 3 months of recovery time. And I'll be good, I'll be good, I'll be a hundred percent just like I used to be. (50-year-old single Black man with mouth cancer)

Unlike other chronic conditions, however, incurable cancer carries with it an ever-present intimation of approaching death and a driving need to cushion that threat not only for the moment but also for the unknown duration of life. Although the process of normalization varies to a certain extent from individual to individual, similarities emerge in how the terminally ill attempt to restore normalcy, maintain personal significance, and guarantee social continuity in the face of death. Because awareness of death is painful and wrought with distress, the terminally ill poor find that focusing on the triumphs and troubles of each day is not sufficient to restore a sense of normalcy to their lives.

> I'm still trying to deal with this, but how good I do would have to depend on what day it was. Some days I do good, and some days I don't. It's like one day you do good, and the next day some little thing gets you off for the while day. That's hard when you're used to keeping things at an even keel. Sometimes I feel like everything's going to be okay, but sometimes I can't get myself together. (43-year-old married White woman with Myelodysplasia)

> I'd just go on and do the best I can and keep on living. I just take life one day at a time. I try to live and let live and not raise any hell. Just keep things nice and steady from morning 'til night. But sometimes late in the day, it get to me. I tell myself the day ain't over with yet. I got to hang on just to see another day. Trouble is, you never know what the day will bring. (68-year-old married Black man with leukemia)

The temporal dimension of the terminal illness experience for the poor cannot be fully understood without reference to the effect that poverty, in general, has on the processing of time. Because a sense of insecurity and instability permeates the daily grind of the poor, they manifest a preference for seeing "the sweep of life rather than its detail" (Rubin, 1976, p. 31). For terminally ill poor, this translates into a temporal orientation where recollections of the pre-illness past become the operative element in the way the self is experienced in the present. As one patient put it, "I told the doctor, this is not going to change me. I'm doing everything to get back to where I was" (46-year-old single Black woman with breast cancer). By hinging their identity on the frame of a known certainty in the past, and interpreting their declining situation as relatively unchanged, patients attain some degree of relief from personal discomfort and social instability. As they weave together the threads of the past to construct a tapestry strong enough to sustain them in the present, the terminally ill poor are engaging in a process of adaptation to crisis rooted in the very fabric of their lives.

For most patients the quest for normalcy involves seeing themselves as essentially the same person they were before they got sick. As one patient asserts, "I'm the same person I was a year ago, yesterday, today and maybe tomorrow" (68-year-old married Black man with leukemia). Because they see the loss of self as the inevitable outcome of the terminal illness process, patients equate life with selfhood. Taking liberty with Descartes'(1637) metaphysical insight on the relationship between rationality and being, it is almost as if the terminally ill poor are saying "I live, therefore I am."

> I want to live to be a hundred and I'm just grateful I've made it this far. I can't, I really don't see where it affects me in no kind of way. It's just for a minute and then I going to get back. I'll get back to my life. I still feel the same way. I'm the same person. It ain't over with yet. (50-year-old single Black man with mouth cancer)

> I said I'm going to stay just where I am. That's the first thing I said when I found out I had cancer. I want everybody to see me as I am. And I don't want a person to be trying to make me out to be better or worse just cause I got cancer. I'm just the person I'm am. I am what you see. After I'm gone, if people want to say what I did or what I was just to build me up, it don't matter. I can't be built up, you know, cause when you're dead, you're just gone. (60-year-old separated Black woman with breast cancer)

> I'm happy just to be me. I've always been me. Nothing's changed about me since I got sick. I am the way I am, that's all I can tell you. I am who I am, and that's who I'll be until the day I die. After I die, I don't know what they'll say about me. I just want 'em to tell the truth. I just want 'em to be honest and not tell no lies about me. (72-year-old divorced White woman with lung cancer)

Enduring qualities of the self take center stage for many patients as they attempt to affirm the continuity of their personhood in the face of death. Focusing on relatively stable elements of identity such as values, beliefs, and personality traits, the patients experience themselves as ongoing entities virtually unchanged by terminal illness.

> I've always been just like I am now. I am a helping person. I'll help you. I'll help anyone who needs it. I feed the birds, you know, the dogs in the neighborhood. Every dog in the neighborhood has a home, but they know me, and they visit me and they sit on the porch with me. I had cats up under my face, just hanging on me. I sit on the porch and if there's a bird, they talk to me and I feed 'em, you know. I'm just a caring person. (53-year-old divorced Black woman with breast cancer)

> I'm still the good person I was before. God has blessed me with a good heart, I would never hurt a fly. I love people, and my heart goes out to the little ones and to the old ones. I am a good daughter, a good mother, a good wife and a good homemaker. I'm a playful grandmother like I think a grandmother ought to be. (57-year-old married White woman with colon cancer)

> I'm still me, myself. I'm just friendly, you know, outgoing, and loves everybody, and I don't hate nobody, never. I have a big, friendly attitude, and more people care about me for that reason than they would if I was, excuse my language, pissing everybody off. (55-year-old married Black man with colon cancer)

While many patients emphasize their virtuous natures, some find consolation in the fact that they have maintained their less than respectable personas and feel no qualms in telling a perfect stranger about it.

> I've always been a lovable, screwy red-headed old witch who knows how to have a good time, and I'm not ashamed to tell you. I'm full of mischief and fun, you know. I'm a happy-go-lucky kind of person. That's something that will never change, I don't suppose. I was never one to take things serious. What's the point of being all grim and solemn and all? I'll tell you what, I'm going to my grave with a twinkle in my eye [grinning]. Won't that be a hoot? (64-year-old divorced White woman with breast cancer)

> I'm a crazy sort and still am for that matter. That's something I've been knowing about me since I was old enough to wonder. I never felt like there was something wrong, but just different in how I see things. See, it's a mind thing. I have my own way of seeing things. I probably shouldn't say anything, you know, but I don't care what Tom, Dick, and Harry say or what they think. I'll let them do it their way, but somebody need to rock the boat. I can just imagine what they'll

> say about me after I'm gone. It don't matter, cause I'll get the last laugh. (54-year-old common-law divorced Black woman with breast cancer)

While some patients maintain a sense of normalcy by holding tenaciously to an image of self with enduring qualities, other subjects assert their pre-illness sense of self by performing the same tasks and maintaining the same routines as before. Focusing on activities from the past that still fill their days, patients experience themselves as actors who remain fully engaged in the routines of daily life.

> Like I said earlier, I'm myself. I'm me. I'm a person and when I act, I act like me. I act like me all the time. I get my son off to school in the morning and do things around the house, that's what I do. I enjoy my grandchildren and my great grands too, you know. I like to fix cookies and stuff like that for them. I don't worry about it, cause it's still going to be like it was. (54-year-old divorced Black woman with breast cancer)

> I don't feel any difference about myself. I'm still living a good life. Nothing has changed in the last ten years except for I did stop smoking. I don't spend my time no different than before. Everything's the same. I pretty much do everything I was doing. I don't act sick. I still go fishing and all that. I still like to cook and clean house. I used to worry about my sickness, but it didn't last too long. I just, just live with it. Living, to be living, is a good thing, it's a good thing. (67-year-old divorced Black man with leukemia)

> Like I said, nothing much has changed. We have never been nothing special if you know what I mean. Before I got sick, me and my dad spent the good part of the day doing stuff. I thought that my life would be just basically like my mother and daddy's. My Dad still comes to the house every day. He's always done that. He's always come by everyday. We watch the races together on the weekends just like during the week we watch some TV. He comes by about the same time every day and we watch some of these court shows they have on TV. (42-year-old separated White man with lung cancer)

Negotiating for Support

As respondents cope with terminal illness over time, they engage in interactional strategies to elicit helpful responses from others and to gain support in the normalization process. As a form of adaption to the cancer diagnosis and a means of equalizing social relations, these strategies have their roots in patients' basic preferences for one of three modes of interpersonal engagement. Patients who prefer to function independently of others in both sickness and in health utilize techniques of resisting and dismissing to limit their exchanges with others. While resisters block the flow of unwanted affect from others by avoiding contact with them, dismissers minimize the value of the affect by discrediting its source. Patients who prefer to function interdependently during good and bad times employ strategies of sustaining and shaping to manage exchanges with others. While sustainers control emotional output to protect loved ones from the stresses of the illness, shapers define the situation for all involved, mandating certain emotional responses and discouraging others. Patients preferring to function dependently in their relationships with others adopt strategies of relinquishing and distressing. While relinquishers elicit positive emotions from others to maximize the potential for social support, distressers produce negative emotions in others to equalize the affective tone of their exchanges. I will discuss each of these types in greater depth in Chapter 4.

CHAPTER 4

COPING STRATEGIES FOR ELICITING SOCIAL SUPPORT

The social support literature documents the importance of instrumental and expressive support in the lives of individuals dealing with stressful life events and highlights the role of subjective perception in interpreting the effectiveness of such support (Ensel & Lin, 1991; Lin, Ensel, & Dean, 1986). While research focuses on the burdens caregivers incur in the social support process (Aneshensel, Pearlin, & Schuler, 1993; Karp, 2001), there is little discussion in the literature of the difficulties patients encounter as they strategize for the type of support they perceive as helpful during stressful times in their lives. While there is substantial evidence that individuals differentiate between helpful and nonconstructive types of social support, there is need for additional research on how victims seek appropriate support and negotiate the boundaries of supportive relationships. A systematic examination of the strategies patients employ to manage and direct caregiving relationships to fit their needs is a necessary first step in grasping the dynamic nature of the social support process. As Thoits (1995) notes,

> Individuals are activists on behalf of their own well-being. That is, people purposefully engage in problem-solving and/or actively reconstructing the meaning of their life experiences in order to sustain their sense of self worth and alleviate anxiety or tension. (p. 58) Stress researchers tend, on the whole, to disregard or de-emphasize the degree to which individuals are activists on their own behalf. (p. 64) But individual activism and motivation become obvious when we examine the effects of coping resources such as mastery and especially when we study the various coping strategies that people deliberately and consciously use. (p. 66)

Despite known benefits of supportive social ties in mediating the psychological effects of stressful life events, social support does not always enhance well-being or alleviate stress (Rook, 1992). Emerging evidence suggests that obligatory social ties within family networks can produce emotional costs that outweigh benefits for both caregivers and patients alike (Berbrier & Schlte, 1993; Gove, Style, & Hughes, 1990; Moen, Dempster-McClain, & Williams, 1989; Rook, 1992; Thoits, 1992; Umberson & Gove, 1989). We are just beginning to understand the process whereby caregivers establish boundaries in relationships with sick loved ones. As Karp (2001) notes,

> Prolonged illness makes demands on a child, parent, spouse, or sibling that test the relative strength of the ties that bind us together. Caregivers must negotiate the boundaries of their involvement with the sick. (pp. 15-16) Anyone who cares for a sick person becomes implicated in their sickness, [and] all illnesses are potentially contagious in the sense that the stories of sick people become deeply woven into the biographies of those who feel a commitment to them. (p. 19) Severe illness, because it so thoroughly disrupts family life, calls attention to the taken-for-granted, normally invisible boundaries of social relationships, [asking] such essential questions as "to what extent are we bound to care for each other?" [and] "what are the limits of sympathy in dealing with another person's trouble?" (p. 30)

While social scientists are well acquainted with the concept of caregiver stress, little attention is paid to the notion of patient stress arising from obligations associated with the sick or dying role. For many patients, the caregiving relationship itself is a major stressor, forcing them to act as agents on their own behalf to manage difficulties created by loved ones. Research suggests that family members often do more harm than good in caregiving roles by overreacting to illness and making demands on the emotional lives of patients that they are ill-equipped to meet (Harris, 1992). As Thoits (1995, p. 66) notes, "family members may push too hard or too soon for evidence of recovery or, alternatively, may become so protective and overly helpful that the victim comes to resent his/her implied dependency."

For low-income and minority populations, economic disadvantage compounds the stress of terminal illness and limits the availability of suitable coping options. As Thoits

(1995, pp. 68, 55) points out, "coping strategies are socially patterned . . . [and] members of disadvantaged social groups are especially vulnerable or emotionally reactive to stressors" so that stressful life events take a heavier toll on them. The difficulty patients encounter in their quest for appropriate social support can be even more complex for the poor, due to the density of their kin-based networks and the absence of weak ties to the larger community. Although the emotional needs of family members can create more stress than their caregiving efforts relieve, the poor often do not have access to suitable sources of social support.

For individuals in this study, the perceived inadequacy of family members in providing appropriate support and the relative lack of real alternatives appear to set into motion a variety of interactional strategies designed to make approaches to caregiving more compatible with the needs of the patient. While negotiating for support takes many forms, based on individuals' preferences for independent, dependent or interdependent modes of relating, common elements appear again and again as patients cope with illness by attempting to elicit the type and amount of support they need. The most important of these elements are the techniques patients develop for managing information and controlling affect. In order to describe the different approaches to support seeking among the terminally ill poor and to illustrate the crucial role of coping styles and emotion rules in the process, representative excerpts from transcribed interviews are used throughout the chapter. As a supplement to the descriptive passages in the text, Table 3 provides a breakdown of patient characteristics by relational category and compares them to the larger sample.

Table 4

Summary Statistics of Major Relational Types with Total Participants

	Major relational types			
Variables	Independent (*n* = 8) (%)	Dependent (*n* = 10) (%)	Interdependent (*n* = 15) (%)	Total (*N* = 33) (%)
Percentage of total	24	30	46	
Race				
Black	87.5	50	87	70
White	12.5	50	13	30
Gender				
Male	50	30	20	30
Female	50	70	80	70
Marital status				
Single (never married)	37.5	10	40	27
Married	37.5	20	20	27
Divorced, separated, or widowed	12.5	70	40	46
Educational level				
<High school diploma	37.5	70	33	48
High school diploma or equivalent	62.5	30	67	52
>High school diploma	50	30	33	36
Church affiliation				
Baptist	62.5	80	73	70
Other	37.5	20	27	30
Time of Diagnosis				
≤18 months preceding study	63	90	60	70
>18 months preceding study	27	10	40	30
Illness progression				
Deceased	87.5	60	47	61
End-stage	12.5	0	20	12
Treatment stage	0.0	40	33	27

Note. The mean age in years for independent types is 58.4, for dependent types is 43.7, for interdependent types is 52.6, and for total participants is 52.

The Independent Mode

Subjects reporting a preference for self-sufficiency and autonomy in interaction with others are classified in the independent mode. For independent types, autonomy and self-sufficiency are personal characteristics differentiating them from others and defining the terms by which they engage their social worlds and frame encounters with others. As the following excerpt illustrates, loss of independence involves not only the forfeiture of a desirable quality but also the imposition of an unwanted change in relational status.

> I've always wanted to be independent. And whenever I have to say, "look, go get me something," that really kills me. My children come when I'm needing things, they come over, and they may not take the money for it, and that aggravates me. I'm going to do my own thing and it's going to stay undone till I get able to do it. I don't want nobody coming in and waiting on me. I don't need nobody coming in and disrupting the way I conduct my affairs and taking charge of my life. (72-year-old White woman with lung cancer)

As Table 3 indicates, the independent types represent 24% (*n* = 8) of the sample with an overrepresentation of Blacks, men, and individuals who have never married, as well as those whose education extends beyond high school. Somewhat older than the sample as a whole, the mean age in years for independent types is 58.4 compared to 52 for the larger sample. Time since diagnosis deviates from the sample, as well, with the independent types reporting a more lengthy disease trajectory. At the time of this report, 87.5% of the independent types have passed away compared to 61% of the sample.

The Resister Type

Independent types who spend time and energy attempting to maintain control of the definition of the situation, discouraging social support and avoiding situations where weakness and vulnerability are exposed, are designated resisters. Constituting 63% of the independent category, resister subjects are 15% (*n* = 5) of the overall sample. While race and gender ratios deviate little from the sample, and educational levels and marital status mirror those of the independent type as whole, resisters report lower levels of Baptist church affiliation. Nearly 60% of the subjects in the study identified themselves as Baptist, compared to 40% of resisters. Underrepresented among patients in the newly diagnosed category, only 40% of the resisters have been diagnosed within the 18 months preceding the study, compared to 70% of the sample. At the time of this writing, all of the resisters have passed away, compared to 61% of the sample.

Resisters cope with the stresses of a terminal diagnosis by keeping thoughts of illness to a minimum, avoiding issues over which they have no control, and focusing on relationships and activities that help them forget they are sick. By not dwelling on illness and keeping as busy as possible, resisters like case 3, a 64-year-old Black woman with breast cancer, are able to keep their illness within manageable boundaries.

> I don't dwell on myself. There's too many things to do. You're so busy you don't have time to just sit. People that sit down and do nothing but think about themselves all the time get sad. But if you're real busy, you don't have time to think about yourself. It goes away because you don't dwell on yourself, and life goes on, so you move from one day to the next.

As a key element of the coping process, resisters cushion themselves against the stress of terminal illness by crafting religious explanations for their situation that put the control of their well-being in the hands of God. By legitimizing patients' thoughts and feelings, this approach frees resisters from the obligation to defend their stance on the illness and allows them to disregard input from others that does not coincide with their perspective. For Resister 2, a 72-year-old White woman with metastasized lung cancer, religion provides a rationale for her plight and reassurance that God will sustain her.

> Well, I feel this way. If God didn't want me to be this way, I wouldn't have this. So, I feel like this is the way it should be. That's the way it is, and maybe if He's seen fit, if He didn't want me to be this way, He could knock it out. The Lord

> ain't going to put on me no more than I can bear. The kids just can't accept that. But I told them, I said, "look, I'll go when the good Lord wants me to go. There ain't nothing we can do about that." And I said "that's just the way it is." So, that's the best I can tell you. If anybody here on earth don't like that, that's just tough. You've got to believe and have faith in Him. If you got any belief at all, you just go on and cope with it like I said.

As a means of reducing stress, resisters utilize strategies of avoidance when it comes to seeking information about their prognoses or formulating ideas about death or disease progression. In addition, resisters erect "information boundaries" between themselves and others to limit illness dialogue with family and friends. Resister 3, a 64-year-old Black woman with breast cancer is a case in point.

> I don't tell them anything. I mean, I tell them a little, but I don't tell them everything. They know I have lung cancer, but they don't know about the other. I told them I had found a spot. They don't know if that's cancer, and they don't know I'm getting chemo, and they want to know why I'm so tired. I just tell them I'm just busy and worn out from doing so much. That way they don't ask questions.

Negotiating social support. For cancer patients, negotiating for support involves a systematic appraisal of their capacity to cope with terminal illness and an evaluation of others' abilities to assist them. Resisters exhibit a preference for a type of social support that raises morale, distracts them from thoughts of the illness, and momentarily frees them from the emotional pain accompanying awareness of dying. Because preoccupation with negative illness outcomes contributes to existential suffering, resisters prefer not to color the present with thoughts of future decline and death. Not wanting to be engrossed in the illness or psychologically burdened by uncomfortable thoughts and feelings, the resisters are determined to keep the illness from invading their minds and taking over their spirits. As Resister 4, a 59-year-old Black man with mouth cancer explains,

> You ain't got to dwell on it. You don't got to constantly keep bringing it up. It ain't like I forgot about it. Cause, you see, a little 5 or 10 minutes of free thinking

> can be good for a mind sometimes. It's just to have that, that freedom in your mind, not having to dwell, not have people bring it up.

Resisters express ambivalence toward the support of others as they draw the line between what is helpful and what is hurtful when it comes to the outpouring of attention. As a case in point, Resister 3, a 64-year-old Black woman with breast cancer, finds it difficult to separate the support she receives from the burden it creates for her.

> [You had a lot of people come visit you haven't you?] Too many. When, I get through with my husband and my sister, and we have two cousins who live with my sister. They won't come together. One'll come one time and the other will come. And so my door is open all the time. I got the chimes on so I know when somebody's coming in, and so my door just chime all day long. They ought to let me get a little rest, but they don't. I don't get no rest. My sister to this day, she cannot accept that I'm sick. She's been coming every day bringing me all this food, and I don't want it. We're just throwing it out, throwing it out, you know.

Because unwanted help can be a burden and a source of chronic stress, acquiring appropriate social support involves a dual process of personal discernment and inter-personal negotiation, as Resister 5, a 46-year-old Black woman with breast cancer, notes.

> I have this girl friend always calling me and say "do you need me to run errands? Do you need me to take you somewhere? Do you need me to take you to the doctor?" And I say "no," and she get mad. Lately, she got upset with me because I wouldn't let her run errands. So then she put $10 in the mail, so I'll go get my nails done. I'm nervous now and I can't polish them straight, so the money really helped. I know she mean well, and there might be a time when I'll be bothering her every day, but right now I can do it, so let me do it. I keep telling her that and she said "okay."

In a similar manner, Resister 1, 54-year-old widowed Black woman with colon cancer welcomes sources of social support that do not excessively intrude into her life.

> [Are you getting all the support you need?] Well, you never get enough good support, you know. I'm just open arms for good support, you know, the kind that doesn't make you feel worse. [Do you turn to anyone, any particular person for good emotional support?] My sister in Atlanta. [How does she support you?] She keeps my spirits up. She just tells me to follow the doctors' orders, and then she'll change the conversation. That means for me not to talk about it. She hints that she don't want us to talk about it, or she'll talk about something joyous.

Managing affect. Because family and friends are dealing with the emotional impact of the illness in their own ways, resisters have to be selective about whom they turn to for assistance. Unsolicited support is a source of stress for resisters, because it rarely fits the affective framework from which they operate. The central dilemma resisters face is how to shield themselves from demoralizing emotions that others express in response to the terminal diagnosis. To protect themselves from the debilitating effects of others' emotions, resisters limit their interaction with individuals who evoke painful emotions and put on "emotional armor" as a shield against unavoidable affective encounters. While Resister 4, a 59-year-old Black man with cancer of the colon, appreciates help from his family, he has to guard against the sentiment he believes generates it.

> [What about your children, how did they react when you told them?] Stuck right with me. [So, to your knowledge, nobody got upset or cried?] No, but I could see the expression on some of them faces at first. [How would you describe that expression?] Daddy ain't that man he used to be. But I try as hard as I can just not to let that affect me. I try adjust my mind to keep their expressions from getting the best of me. My saying, whether right or wrong, I feel your mind controls your body, and I feel like if you don't get your mind adjusted to where what other people say don't bother you, it's going to make you feel worse.

For resisters the greatest threat to emotional well-being is pity from others, not only because feeling sorry for another implies they have a "spoiled identity" or an impaired self, but also because it takes the definition of the situation out of the hands of the patient. By it's very nature, the dynamic of giving and receiving pity involves a social exchange in which the parties are essentially unequal. As Resister 5, a 46-year-old Black woman with breast cancer, explains,

> I don't want people's pity. Pity don't make this easier on me. I can't say about nobody else, but for me, don't feel sorry for me. Let me try to do what I can for myself. Maybe I shouldn't look at it so sensitive, but that's the way I feel. [So you think there might be a connection between independent people and people who don't want pity because they think that it will take away their independence?] That's right. I don't want nobody feeling sorry for me and telling me what to do.

To frame the situation in a more positive light and discourage the emergence of pity, resisters utilize strategies of self-presentation management, as Resister 1, a 54-year-old widowed Black woman with colon cancer, illustrates.

> I try to keep my appearance up. Like I comb my hair, take my bath, you know, put my clothes on. Put on, if you wear make-up, put on a little, you know, be yourself. Then my, this is my son, "oh, Ma, you feel good, you look good today." He be smiling because he knows that's the way I am. I'm used to putting my clothes on, and, so, you know, like if I lounged in my gown and robe, when he comes by, and I'm lying down or something, he'll start looking at me with that pity look in his eyes like a I'm a sick person or something.

Because expressions of pity are interpreted as threats to independence, resisters like Case 4, a 59-year-old Black man with colon cancer, "put on" emotional facades to fit the images they want to project to others and deter expressions of unwanted sentiment.

> I'm a very proud man. Like you see, I was sitting in the waiting room out there, and I was feeling more nauseated than I ever been, so I just sit there and shut my eyes and try to look normal. I just want to be feeling peppy or whatever, you know. [It looks like you're peppy to me.] Well, I hope it appears that way. [So it's important to you to appear that way?] Sure it is. [Do you think that affects how people relate to you?] Sure do. I try, I want them to relate to me that way. I don't want them to look at me with pity. I try to carry myself in a way that my friends don't have to pity me or whatever, you know. I hope that they would treat me, and most of them do, not as an invalid like it's something catching.

As a theoretical category, resisters are a subgroup of the independent type that utilizes strategies of avoidance and self-presentation management for generating the kind of social support that will sustain rather than thwart them in their efforts to defuse the demoralizing capacity of terminal illness. To refine our grasp of the independent mode as a whole and to clarify distinctions between its two types, it is necessary to compare and contrast the resister type with its independent counterpart of dismissers, identifying areas of convergence as well as paths of divergence between them. Like resisters, dismissers expend energy attempting to keep others at bay, but unlike resisters, who take a defensive stance, dismissers do so in a way that puts them on the offensive.

The Dismisser Type

Independent types who engage illness in a stoic fashion and minimize its impact on their lives are designated as dismissers. Comprising the smallest group, dismisser subjects account for 9% (*n* = 3) of the sample. From the perspective of gender, race, and religion, dismissers are a homogeneous group. While Black men account for 21% of the sample, they comprise the entire category of dismissers. Dismissers deviate from the sample in other important ways, as well, with lower levels of married subjects and higher levels of individuals with post-high school education or training. All of the dismissers have been diagnosed within 18 months of the study compared, to 70% of the sample. At the time of this writing, 66.6% have passed away, compared to 61% of the participants.

With an approach to life that is matter-of-fact, realistic, practical, skeptical, and down-to-earth, dismissers are not impressed by the power of the illness to compromise their lives. Unlike resisters, whose lives revolve around efforts to avoid the unwanted consequences of their illness, dismissers minimize the trauma of terminal illness by interpreting it as a minor inconvenience rather than a major life event, preferring not to expend a great deal of time and energy attending to it. Unlike resisters who adopt coping strategies that buffer them from external sources of stress, dismissers employ strategies designed to boost their internal sense of control. Utilizing techniques of downward comparison, dismissers try to minimize the seriousness of their condition and enhance their sense of mastery over the illness. Although dismissers experience some degree of physical impairment from the illness, they discount it as a temporary setback. Dismisser 3, a 55-year-old Black man with leukemia, is a case in point.

> My minister is just about worse off than I am, and he was down and out, so he's in pretty bad shape, and can't do much. But I don't have side effects or nothing. I feel like I can do anything if they give me a handful of pills and let me go. It's

> just an illness I got to deal with, that's all. Sooner or later I'm going to beat this. I'm going to heal.

While resisters manage the impact of information directed at them by rejecting interpretations of others, dismissers control the need for information directed at others by minimizing the importance of dialogue about the illness. Believing the illness to be of little consequence, dismissers are reluctant to reveal its details out of fear that others will exaggerate its importance. As a case in point, Dismisser 1, a 50-year-old single Black man with throat cancer, is reserved, reticent, and evasive in encounters with his sisters.

> [Do you feel like the doctors provided you with the facts you needed?] They did all I asked. If it was up to my sisters, they'd ask more questions, because they feel like I don't ask enough questions. Both of them do. They want me to ask more questions, so they can get more answers. What they don't know is I wouldn't tell them anything even if I knew it. They try to make a big deal out of everything, so I got to hold back on what I tell them.

Negotiating social support. For dismissers, negotiating for support involves trying to convince others that no support is needed. While resisters worry about the impact of demoralizing social support on their capacity to sustain emotional well-being, dismissers are unequivocally opposed to almost any type of social support because of its potential to compromise their sense of mastery. Exhibiting a strong sense of self-efficacy, Dismisser 3, a 55-year-old Black man with leukemia, is a case in point.

> I never looked forward to nobody ever helping me. Myself to you, I got to live. You got to live so, you know, do it, you can. Same as I do, you can. You can go for it. You've got goals you want to achieve and everything that you want to do. Go out there and reach for it, get off of your lazy butt and do something. I don't believe that those psychiatrists, social workers, well-meaning people and all can help me. They can solve a problem that day, you know, whatever we're talking about, but you still got that problem. I'd listen to them or whatever but, I feel like the problem is within yourself. And you can help yourself by doing the things you know you can do daily. I don't think nobody should be doing anything for me. I think I should be doing it for myself.

To deal with adversity, dismissers need to feel as if they are competent to manage whatever contingencies come their way. As a means of boosting self-confidence in the face of terminal illness, dismissers exaggerate their capacity to go it alone and discount their need for others. Detaching themselves from the illness as a way of minimizing its impact on their lives, dismissers brush off others' attempts to engage them in illness-related exchanges of information or affect. Turning to God as a source of empowerment, dismissers see themselves as agents capable of acting on their own behalf. In much the same way as resisters, dismissers utilize a religious framework to shape their approach to coping. Unlike resisters, however, who attribute illness outcomes to a higher power, dismissers turn to God to increase their sense of mastery and enhance their internal locus of control. Dismisser 2, a 68-year-old married Black man with leukemia, is a case in point.

> There ain't but one healer in the whole world, and that is God [pointing up to the heavens]. He controls everything, me, you, and everybody else. He's the only thing that can heal. All you got to do is put your faith and trust in God. Prayers change a lot of things. You pray and talk to the boss up there, and you'll get an answer. You might not get it all the time, right on time, but you get it. I take him all my troubles. If I got any, I talk to the Master. He's the man to go to.

Managing affect. Unlike resisters whose independent stance does not insulate them from the interpersonal dynamics of family and friendship, dismissers coexist with family and acquaintances without engaging them in any systematic way. A key dilemma for dismissers, therefore, is how to manage relationships without investing too much of self in the process. Limiting the flow of affect toward others is a major way to approach this task as Dismisser 2, a 68-year-old married Black make with leukemia, illustrates.

> I left my feelings in Korea when I was over there, 'cause that's where my feelings are left— right there in this rice paddy somewhere down there. I just left my feelings there because I didn't, I don't want help from nobody. Don't go and start trying to help me. Help yourself if you want someone to help. I'm not one to sit

> around and mope around and give up on living. I want to stay here. I want to stay here as long as I can.

Experiencing himself as a self-contained entity capable of meeting his own needs, Dismisser 1, a 50-year-old single Black man with mouth cancer, discounts the need for help-seeking behavior and assumes a stance of emotional self-sufficiency as a reflection of patterns rooted deeply in his earlier years.

> [Can you talk honestly with anyone about your feelings and concerns?] Several people, but I don't. [Why don't you?] Well, I don't know, to be honest with you. I really do not know. It might be the way it is me being the older boy growing up with two sisters. My two sisters used to play together all the time. I had to make my own, so it was always me when I grew up. Everything that stayed inside of me was mine.

With the onset of terminal illness, dismissers find it necessary to tighten the reins on their affective expression to discourage unwelcome intrusions into their emotional lives. Dismisser 1, a 50-year-old single Black man with throat cancer, detaches himself from household dynamic, leaving the decision making in the hands of others.

> It's my mother house. I came to stay with her about 25 years ago. We just stay under the same roof. You got to talk to my sisters about mother. They're over there most of the time since I got sick. They've been going to the house a lot and cleaning up and throwing stuff away, "Well, do you want this, what you going to do about that, how do you feel about this?" "I don't care. Throw whatever you want to throw away," I tell them. I don't have any feelings about what they done one way or the other. I ain't getting started with them, 'cause before you know it, they'll be running my life.

Similarly Dismisser 2, a 68-year-old married Black man with leukemia, reduces opportunities for emotional exchanges with loved ones by limiting encounters with them.

> I have 5 girls and between 20 and 25 grandchildren. [Your daughters had a lot of children.] Ya, too many, but I don't let them stay here. They just come to visit and whoosh, I send them on their way. So, I stay out of their business, and they stay out of mine. I don't get into all that kind of stuff with them. I don't let them stay around long enough to see how I'm doing and I tell them not to call every day. When I call, I just call to see how they're doing. I'm gone.

As a theoretical category, dismissers represent a small but intriguing subtype of the independent approach to managing the experience of terminal illness. Adopting a strategy designed to minimize the necessity of attending to the illness and downplay the need for engaging others in the process, dismissers prefer to rely on their own resources rather than the support of loved ones. Although the dismisser type contrasts with the resister type in their approach to the illness and their encounters with others, together they represent how autonomous individuals navigate the terminal illness experience.

The Dependent Mode

Subjects reporting a preference for deferring to authority and relying on others for care and support are designated as dependent types. While the dependent mode involves being sustained physically and emotionally by another, its hallmark is how patients are subject to someone else's definition of the situation. Lacking a sense of individuality and self-determination, dependent types experience themselves solely through the eyes of others, as the following excerpt illustrates.

> I often wonder how I have changed personality wise and character wise and all, 'cause I don't realize how I used to be before I got sick. Now I wonder how, if it has changed me. [Would there be some way that you could find out?] Probably, I just don't talk to many people any more. I don't hang around with the same friends and everything. I could, well my mother is gone and I'm not, that close to my daddy, so I just, I just have to depend on, the friends I do have. I haven't keep it touch with any of my high school friends, so I guess it'd be hard to find out. (34-year-old White woman with Hodgkins disease)

Representing 30% (*n* = 10) of the sample, dependent subjects are characterized by an overrepresentation of Whites, individuals who are divorced or separated, and those with less than a high school education. As Table 3 indicates, while Whites make up 30% of the sample, they constitute 50% of the dependent types. White men comprise 20% of the dependent category but only 9% of the sample, while White women represent 50% of the dependent type but 21% of the sample. The overrepresentation of divorced and separated subjects is quite marked, as well, with 70% of dependent subjects reporting prior domestic relationships compared to 46% in the sample. With 70% of dependent subjects lacking a high school diploma, the dependent types exceed the 48% school drop-out rate seen in the sample. Somewhat younger than the sample as a whole, the mean age in years for dependent types is 47, compared to 52 years for the larger sample. Religious affiliation of dependent types varies slightly from the sample, as well, with 80% claiming to be Baptists, compared to 69% of the sample. All but one of the dependent subjects, or 90% of the category, was diagnosed within the 18 months preceding the study, compared to 70% of the sample. At the time of this writing, 60% of the dependent subjects have passed away, compared to 61% of the sample.

The Relinquisher Type

Dependent types who give up their right to self-determination and turn over the responsibility for their care to others are categorized as relinquishers. Placing confidence in the ability of others to interpret the situation, Relinquishers exhibit patterns of passive acceptance of their illness and unquestioning belief in their caregivers capacity to sustain them. As the larger of the two dependent types ($n = 6$), relinquishers account for 18% of the total participants, with an overrepresentation of White, divorced, and less-educated subjects. With an average age of 43 years, relinquishers are relatively younger than the sample mean of 52 years. All but one, or 90% of relinquishers, have been diagnosed within 18 months of the study, compared to 70% of the sample. At this time, 66.6% of relinquisher subjects have passed away compared to 61% of the sample.

Relinquishers cope by constructing social worlds in which the burden of sustaining their personal well-being is the responsibility of a designated adult whom they perceive as more competent than they. Allowing themselves to be rescued in their time of need, most relinquishers rely almost exclusively on this one individual to manage the illness. Attributing idealized qualities to caregivers, relinquishers such as Case 2, a 52-year-old divorced White woman with cervical cancer, idolize their caregivers and rely on their expertise to manage the illness.

> [How long did you have the symptoms before you went to the doctor?] About two weeks. [So you didn't put it off at all?] No, my sister wouldn't let me. If everybody had a sister like I got, this would be a better world, believe me. My sister, she's the only one I got, she's my God bless. If it wasn't for her, I don't think I would have made it this far. I cried a lot for about a week or two, and then my sister, she said, "up and at it, we got to get out of here, we got to get this thing going now." So, that done it. She's always been, she's a pick-me-up person, you know, "we've got to do this, we've got to do that, and you've got to get this over with." And I'm proud. You'd just have to meet her to believe her. She's something else.

A distinctive aspect of the relinquisher approach to coping is the relative absence of references to God. Although most relinquishers have early ties to the Baptist church, religion as a way of framing reality has lost its hold on them. Unlike independent types who place God at the center of their coping scheme, relinquishers do not see the hand of God at work in their illness. Relinquisher 3, a 50-year-old single Black man with stomach cancer, is a case in point.

> [Are you presently an active member of any church?] No, I don't go too often any more. I don't feel like there's much God can do for me. [Do you feel like what happens to you is under your control rather than under God's?] No, I sure don't. [Who's control is it under?] I guess it's just in control on its own. But I don't think it's the Lord that did it or even the smoking or drinking that did it. I didn't make the decision to take care of my body, so the body can let you down, but I think it's just on it's own. [So you don't think it's something the Lord gave you or something the Lord can help you with?] No, I don't.

As passive recipients of information and advice rather than active agents in the communication process, relinquishers rely heavily on others' input. Expressing doubt, discomfort, confusion, or inaccuracy in response to queries concerning the specifics of their medical conditions, relinquishers prefer to yield to the superior judgment or formal authority of others. Exhibiting a lack of specificity about her prognosis, Relinquisher 5, a 43-year-old widowed White woman with myeloid cancer, is a case in point.

> [Who told you that you have cancer?] Is that a cancer? [Oh, since this is a cancer clinic, I was just thinking maybe you have cancer. What is your understanding of what the doctor told you about the seriousness of your illness and your chances of survival or cure?] Um, they hadn't really told me what my odds are. They just told me that my bone marrow wasn't producing any cells. [Have they said anything to you about a cure or if you'll survive?] If they did, I don't remember it. [If you could do it over again, would you rather not know how serious it is?] It wouldn't really matter to me. I just, you know, I, I don't know. I think they'll do the best they can and not make me worry when I might not have to.

Overwhelmed by feelings of shock, sadness, and self-doubt, relinquishers' inner lives are filled with fear of the unknown. Because caregivers try to shield patients from stress by presenting an overly optimistic assessment of the situation, relinquishers have to deal with painful contradictions concerning their health status. Communicating a false picture of hope, caregivers color information so that it appears in a more favorable light. In spite of undeniable evidence of disease progression and physical decline, relinquishers feel obligated to believe what their caregivers tell them and ignore their intuitive sense of what is going on. Relinquisher 1, a 43-year-old divorced White man with lung cancer, is a case in point.

> I'm scared about what's going to happen and nobody is telling me much. They tell me not to worry cause everything is under control. I feel like they can control it so far, but like, I don't know how long they can control it. I feel sad and I feel if it was to get out of control, if something was to go wrong, I'd have to leave my kids, and I wouldn't be able to deal with that. The biggest problem is my kids, you know, how to tell them and what to tell them. I don't want to scare them, but to tell the truth, I'm pretty scared too.

Negotiating social support. For relinquishers, negotiating for support involves sustaining caregiving relationships already set in place. With a history of stressful life events that compromised their sense of mastery and took a toll on their capacity for self-sufficiency, Relinquishers exhibit deep-seated preferences for depending on others. The trauma of divorce stands out as one of the defining pre-illness experiences in the lives of relinquishers, forcing them to move in with or relocate near family members to survive. With a history of unstable living arrangements, relinquishers have been depending on the support of others for extended periods of time. Utilizing tactics of submissiveness and cooperation to insure ongoing care, relinquishers give lip service to caregivers' stances toward coping. Attempts to adopt another's coping style prove too difficult a task, however, failing to yield positive mental health outcomes for relinquishers who continue to struggle with depression. Immersed in relational dynamics of dependency, they accept whatever support they can get in spite of the emotional burdens it imposes on them. Relinquisher 3, a 50-year-old single Black man with stomach cancer, is a case in point.

> The people around me, family, friends they give me more support than I need. They always help me and tell me to forget about the cancer. When everybody treats me that way, half the time I forget about the cancer, to tell you the truth. It don't bother me until after they leave, cause pretending the cancer ain't there won't make it go away. I start feeling worse than before. I enjoy having people around me, so that's the price I got to pay.

Unlike independent types who differentiate between helpful and hurtful forms of social support, relinquishers' desperate situations compel them to accept whatever help is offered. Embedded in pre-existing patterns of dependency and governed by feeling rules, relinquishers cooperate with caregivers to insure ongoing care. For Relinquisher 1, a 43-year-old divorced White man with lung cancer, the death of loved ones compounded the pain of divorce and diminished his capacity to function autonomously.

> I lost my mama and oldest brother in '92, and my oldest sister, she died this past year. Daddy's been dead and buried close to 20 years. Right after daddy died, I started having seizures, so they put me on medication. After my divorce, I started having them pretty regular, so I moved in with a friend in Woodlawn. Before the divorce, me and the wife and kids, we had a place of our own, but I've been living with my sister and brother-in-law for the past year or so. I try to be good, so I won't cause no trouble. I don't have anywhere else to go.

Managing affect. Relinquishers' relationships with caregivers are marked by an unequal distribution of power. An absence of reciprocity sets the stage for the emergence of a childlike stance on the part of patients, who tend to assume submissive roles in the caregiving dynamic. Relinquisher 2, a 52-year-old divorced White woman with cervical cancer, illustrates this point.

> [Does anybody else live with you besides your sister?] No, just, just her husband. [Are there any children living in the home?] Nobody else, just, I'm the only kid. [Is she your older sister?] Ya, she does anything. She sits there and talks to me. She says, "look, you need to do this. I'm not telling you to do it, but you need to do this, you need to see to it. Did you take your medicine on time?" [How does that make you feel?] It don't bother me none, cause I know its for my own good.

Relinquishers experience reality through the affective frame of caregivers who try to generate desired emotions from patients by telling them how to think and what to feel. Just as young children construct their emotional worlds out of material provided by their parents, relinquishers attempt to make their feelings conform to those permitted by their caregivers. Because their emotional life is directed by others and does not correspond to what they actually feel, relinquishers experience an added sense of burden. Obligated to comply with the wishes of caregivers, relinquishers struggle to follow emotion rules. Relinquisher 4, a 37-year-old divorced White woman with breast cancer, tries to put on a happy face even when it is a poor emotional fit.

> [Do you turn to anyone in particular for emotional support?] My mother. [And how does she support you?] If I want to sit down and have a good cry, she let's

> me sit down and have it. And then she says, "well we ain't going to have it no more. Go on, think positive." My mother won't let me get down or talk negative. She tries to keep me from getting depressed. I still get depressed, but she don't want me to feel that way. I try to have a jolly attitude. Why not be jolly? And maybe some of it will rub off. I can joke about anything. I mean, I'm not the type to make light, and I might be hurting inside, but I'm joking with everybody else.

Struggling with the emotional tone set by her caregiver, Relinquisher 6, a 34-year-old divorced White woman with Hodgkins lymphoma, tries to put aside negative feelings and generate positive affect, but she has difficulty doing so.

> My boyfriend tells me I'm strong and I'm a fighter. I don't feel like I'm fighting anything or being strong, because I get depressed a lot of the time. And I don't know why he thinks that I'm strong or a fighter, because it's not me. Some days, I don't have the energy to put up a good front for him, but most of the time I try. I'm afraid he'll stop taking care of me if he thinks I'm not trying to beat this.

In spite of caregivers' good intentions, the task of assuming a parental role in the lives of patients has unwanted consequences. For relinquishers, being treated as a child seems to generate some childlike emotions, as Relinquisher 5, a 43-year-old widowed White woman with myeloid cancer, relates.

> Sometimes I think people expect too much from me. They have always leaned on me and stuff, and I don't have the patience I used to have then. Sometimes they just don't understand. I get grouchy sometimes, and pout. I don't know why I act that way, but I guess its the cancer.

The relinquisher type provides a way to frame and interpret the illness behaviors of a relatively small, but theoretically robust, segment of the sample. For relinquishers, coping with terminal illness involves efforts to insure ongoing care by adopting care-givers' definitions of the situation and complying with their feeling rules. To understand the distinctiveness of this approach to illness, it is necessary to distinguish relinquishers from their dependent counterparts, the distressers. Although distressers have many traits in common with relinquishers, such as their need to be cared for by others, they exhibit important differences, making them stand out as a viable category in their own right.

The Distresser Type

Dependent types who experience unusual difficulty managing the overwhelming emotions associated with life crises, in general, and terminal illness, in particular, are designated as distressers. Constituting 12% ($n = 4$) of the participants, distresser subjects are the smaller of the dependent types, with a gender ratio reflecting both the larger category as well as the sample as a whole. Although equally divided between Blacks and Whites, distressers deviate from the total sample which has a ratio of 70% Black to 30% White. With an overrepresentation of White subjects, as well as individuals with lower levels of educational achievement, distressers mirror the dependent type as a whole. Older than their relinquisher counterparts, distressers have an average age of 52 years. Compared to 70% of the sample, all of the distressers have been diagnosed no earlier than 18 months from the start of the study. At the time of this writing, 50% of the distresser subjects have died, compared to 61% of the sample.

Coping is especially difficult for distressers, not only because, as dependent types, they are not well equipped to deal with it alone, but also because the chronic nature of their problems has diminished faith in their capacity to cope. Due to a series of tragic events shaping their lives, distressers are no strangers to emotional hardship and family difficulties. Distresser 3, a 60-year-old separated Black woman with breast cancer, is a case in point.

> I have one brother deceased. I think he was doing drugs. That was back in '89. My oldest son was an alcoholic, and he moved back here in '91. There was a lot of problems during that time when everything in my life started coming down. And then in '92, things were a little better but not the best, and then my auntie went in for surgery, and she died, and that caused a little thing. I have a sister that died in 1994 and my oldest son died in '95. Every time somebody dies in the family, there's always problems. I guess you could say from '91 on, I just really did have a lot of problems. It's like I don't have that healing time. And now this. I don't know how I can make it through this too.

Unlike their relinquisher counterparts, who rely heavily on social support to buffer the physical and emotional stress of the terminal illness experience, distressers surround themselves with individuals who are as emotionally vulnerable as they and equally incapable of handling the effects of stressful life events. For distressers, the daily hassles and chronic strains of everyday life translate into insurmountable barriers to well-being. As a case in point, Distresser 2, a 57-year-old married White woman with colon cancer, recalls a pre-diagnosis life characterized by unrelenting stress.

> I was tired, and I was under a lot of stress. Mother was running me to death all the time, you know, wanting me to go over there all the time. And I just couldn't say "no" to her. My husband, he wasn't feeling right. He's got diabetes and severe hypertension, and he's had four bypasses done. I was having to run back and forth to the VA hospital with him and take care of mother and my step-daddy and sit up at the hospitals with them when they was sick. It was a real mess.

Because distresser families are enmeshed and susceptible to emotional contagion, they are often caught in a spiral of anxiety. Expending large amounts of time and energy constructing hopeless and helpless views of reality, distressers infect others with worst-case scenarios. Dependent on the excessive emotionality of others to acknowledge and legitimate their troubles, distressers generate painful emotions in others to assure themselves of their love. Uncertainty about treatment options and illness outcomes feeds the distresser dynamic as patients use information to control the emotional dynamics of their households. Entangling her family in an emotional tug of war over her plan of care, Distresser 2, a 57-year-old married White woman with colon cancer, is a case in point.

> At first, when the doctors told me, I shut my eyes and I wouldn't listen to nothing they had to say. I kept telling people "I don't have cancer, I don't have cancer." I think I shocked all of them at first 'cause I told them that I wasn't going take any treatments. I wasn't going to take chemotherapy 'cause I was afraid. But, when I talked to the doctor and he says that it had grown 45% more, they got real upset. Everybody started carrying on, so I agreed to have this chemotherapy. But something kept telling me, you know, I just don't want these treatments, because the things you don't know about, you know, can scare you to death.

Negotiating social support. For distressers, negotiating support involves attempts to sustain caregiving relationships that offer an outlet for stress and validate their woes. Unlike relinquishers who are dependent on caregivers for interpreting the situation and buffering the illness with positive emotions, distressers rely on caregivers to replicate the painful emotions and assume some of the emotional burden of the illness. Embedded in a dynamic of excessive emotionality, relational patterns of distressers are characterized by an overemphasis on closeness and an immersion in the lives of others. Appearing to function as an extension of a larger group dynamic and seemingly incapable of emotional individuation, distressers are unable to differentiate from their loved ones. Manifesting permeable boundaries, the relationships between distressers and caregivers are sources of personal stress and interpersonal strain. When illness intrudes into their lives and the levels of stress and strain approach critical proportions, distressers rely on loved ones to absorb and reflect their suffering. A case in point, Distresser 1, a 52-year-old divorced Black woman with colon cancer, describes the impact of her diagnosis on her family.

> My daughter and her husband both took off that day from work to carry me to the hospital. When we got the news, I was so upset that she got upset. "Oh, not my mom. Oh, baby, I'm so sorry. I'm going home to get your insurance papers ready in case we have to bury you." I had to comfort her, and she had to comfort me. And the doctor, I know he thinks we was crazy. [Your son-in-law, did he get upset as well?] Yes, he's very close, like I say, we're very close. He cried. My daughter cried. They both love me. They said, "mom we love you."

Unlike relinquishers who ensure ongoing support from caregivers by keeping the affective expression within acceptable boundaries, distressers hold on to caregivers by spreading emotional distress outside of personal boundaries, so that it infects others and binds them to the patient. Unlike relinquishers' families, where the distinctions between patient and caregiving roles are clear, distresser families blur the lines of demarcation between patient and loved ones so that caregivers often become patients as well. As a consequence, patients worry about the distress of family members and experience guilt over the pain they are inflicting on others. As a case in point, Distresser 4, a 42-year-old divorced White man with lung cancer, is concerned about his mother's emotional well-being but unable to alleviate her distress.

> I know this is putting a big strain on my mother because her, her having to take care of everything, pay all the bills, and she's the one that makes sure I get here when I need to be here and get my medicine filled when I need it, and I just know it's just got to be real hard on her. I wish there was something I could do to make things better. I feel so bad about making her upset. I hope my mother doesn't have to suffer much with this [tears]. The doctor put her on pills for her nerves, but she still cries all the time. I know it's my fault, but I can't help it.

Reluctant to seek outside help in moderating the stress that illness brought into the home, Distresser 2, a 57-year-old married White woman with colon cancer, depends on her husband's distress to validate her emotional life.

> [Did your husband react okay?] Not really cause he depends on me. I do all the bed pan, and I do all the, all the decision making, and he depends solely on me for everything. And he's not taking it very well. But I keep telling him, this is what this is all about. It's about me getting through this. I'll do anything to get through this even if it upsets him. [Well, have you ever heard about hospice home care?] Ya, my step-daddy had hospice. [Do you think that hospice could help you?] It probably could, but I just don't feel like I need 'em. I just want to be with family. They know me better than anyone. They understand how I feel about things.

In a similar way, Distresser 3, a 60-year-old separated Black woman with breast cancer, tests the devotion of her son on whom she is dependent for reassurance and care.

> When my grandson graduated from middle school, I couldn't go, so they came by and got me for pizza so I wouldn't be left out. When I got in the restaurant and got in line, I started hurting, and I'm thinking I can't stay here. So, when my son turned to look at me, I said "I can't make it." They got my daughter-in-law to carry me to the car. I had broken out in a sweat, 'cause I was struggling to stay on my feet. When they got me home, I promised my son I wouldn't go anywhere else 'cause I realized I couldn't make it in that condition. My son was relieved, a little too relieved, if you know what I mean. Later that week, I went out to get my hair cut, and when he found out, he was so upset. "Mama, why did you do that? You know you shouldn't be going out. You're going to worry me to death." I didn't mean to upset him, but I wanted him to know I still needed checking up on.

Managing affect. Experiencing themselves as victims, distressers operate out of a sense of unfairness and are subject to feelings of self-pity. Unlike relinquishers, who are saddened and frightened by the diagnosis, distressers are embittered by its randomness. Feeling as life has dealt her another unfair blow, Distresser 3, a 60-year-old separated Black woman with breast cancer, engages her illness with a sense of deprivation.

> [What's it like for you to have cancer?] I just feel overwhelmed. I feel like it shouldn't be me, I mean, why should I be the one? You know what? Everything happens to me. I'm one of those people who got the long form from the census bureau. I should have know that this wasn't going to be my year. I have always been shortchanged. And after this happened, I asked, "what am I here for? Why is all this happening to me?" It's just not fair.

Unlike resisters, who avoid pity at all costs, distressers need pity from others to validate their sense of injustice and insure ongoing significance in the family's relational dynamic. The key emotional task for distressers is to elicit desired levels of expressive sentiment without overwhelming caregivers to the point where they are incapable of functioning effectively in a supportive role. Distresser 3, a 60-year-old separated Black woman with breast cancer, controls the affective dynamics of the family by withholding positive data and revealing information that is likely to generate emotional responses.

> I told the doctor not to sugar coat anything for me, and when I talk to my family, I don't hold back. I just feel like it's a fact that the doctors may not be able to get it all [the cancer], so why pretend that everything will be okay? They always said I had a few cancer cells left, or whatever. Even though they said the chemo should take care of it, they never said I had a good survival rate. So I don't tell my kids anything that would get their hopes up. Like I said before, my son and the rest of them are going to have a hard time grieving when I'm gone, so as much as I hate it, I tell them the worst, even if they start carrying on.

As a sensitizing concept, the distresser category represents a way to grasp the dynamics of dependency in relationships where unbounded emotions drive the terminal illness process. Unlike relinquishers, whose caregivers set limits on affective expression, distressers push the limits of emotional expression as a means of generating support. As dependent modes of engaging terminal illness, distressers and relinquishers alike provide windows into the dynamics of patient-caregiver interaction when patients rely on loved ones to assume disproportionate responsibility for their well-being. Unlike independent types, who prefer to keep loved ones on the periphery of their lives, relinquishers and distressers strategize for the type of social support that will keep them at the center of the family dynamic and insure continuity of support. Like the independent types, however, relinquishers and distressers are not free of the burdens of illness as they struggle with feelings of depression, guilt, and sorrow over the pain they bring upon themselves trying to conform to others' expectations and generating anguish in others.

The Interdependent Mode

Subjects reporting a preference for reciprocity and mutuality in relationships with others are categorized as interdependent types. Representing 46% (n = 15) of the sample, the interdependent mode has an overrepresentation of unmarried, female, and Black subjects with at least a high school education. While women make up 70% of participants, they constitute 80% of the interdependent type, and while Blacks constitute 70% of the sample, they account for 87% of the interdependent category. Over all, Black women comprise 73% of the category, compared to 46.5% of the sample. Compared to 27% of total participants who are married, only 13% of the interdependent types have spouses. Adopting a stance of mutual support, interdependent types exhibit a preference for the "give and take" of reciprocity. Unwilling to relegate their care to others and unable to make it alone, interdependent types try to strike a balance between the two extremes.

> Let me control some of my life. And I think family members and especially my children do not do this. We've been exposed to a number of deaths this past year-and-a-half. So my girls are right on me, you know, in a sense, they haven't given

> me room to breathe, saying "Mama, put this on today or come and go with me" whether I feel like it or not. I realize they feel like they're doing the best thing, but some of me says I don't have to let them do it just because they want to. You have to get used to the fact that you're no more in control now or in charge, because you've exposed members of your family to whatever's happened to you, and like I say, it always involves somebody. But, then, I'm beginning to realize my daughters can do some of the things I didn't give them credit for, you know. (63-year-old Black woman with breast cancer)

The Sustainer Type

Interdependent types who define terminal illness as a battle to win or a difficulty to endure are designated as sustainers. Comprising 18% ($n = 6$) of the sample, sustainers, like the interdependents as a whole, are overwhelming Black, female, and relatively well educated, with Black female high school graduates making up 83% of the category. With an average age of 54 years, sustainers are only slightly older than the sample as a whole. Equally divided among married, single and divorced, separated, or widowed, sustainers have a higher percentage of single subjects than the sample. While 70% of participants have been diagnosed within 18 months of the onset of the study, only 50% of sustainers have been. At this point, 50% of sustainers have passed away, compared to 61% of the sample, and one of the surviving sustainers is in the end-stage of her illness.

Engaging terminal illness with a fighting spirit and a will to survive, sustainers believe triumphing over adversity makes them stronger, better persons. Concealing from others the seriousness of their cancer or the extent of their emotional and physical pain, sustainers modify the definition of the situation in an attempt to manage the emotions of loved ones and cushion the impact of the illness on them. Adopting a survivor mentality, sustainers exhibit faith in their ability to endure and to experience personal growth in the process. Sustainer 4, a 49-year-old Black woman with breast cancer, is a case in point.

> You just have to hold your head up, and fight the good fight. Sometimes people are not able to do anything, and they just roll into the grave before their dead, but I'm a fighter. I get stronger with each small victory. I'm praying that I have a long life, good health and a positive future.

For sustainers, coping with terminal illness involves adopting the ideology of the war on cancer. Experiencing themselves as warriors in battle against a dreaded disease, sustainers believe in their capacity to triumph over adversity and emerge victorious. Bravely facing the challenges of life-threatening illness, sustainers experience themselves becoming stronger and more capable in the process. Sustainer 5, a 42-year-old Black woman with breast cancer, illustrates this point.

> Dealing with breast cancer, it's been the experience of my life. Just being the strongest one and coping with it, no one else but me is coping with it. [Do you think you are coping better than anybody else in your family?] Yes, I am. I think I'm a winner. I'm a fighter. I can beat this.

A major element of the coping process, faith in God functions as armor to shield sustainers from the harsh realities of terminal illness, providing them with a resource that does not diminish as the illness progresses. As the only constant element in the terminal illness equation, religious faith is a bulwark that protects sustainers from the onslaught of fear. Sustainer 5, a 42-year-old Black woman with breast cancer, is a case in point.

> I really got closer to God, and this illness has been a blessing. It may sound kind of weird being sick, but to bring you closer to God and let you know that he is taking care of you. The doctors tell me that things don't look too good. But I try to stay calm and don't let it scare me. You know, it's not what man says, it's what God says. He lets me know that when things get bad, He will shield me. When nobody's there, He's there all the time.

Sustainers utilize a selective approach in communicating facts about their disease progression and health status. Feeling that everyone cannot handle the same information, sustainers customize disclosure to fit their perception of others' capacity to cope. As a case in point, Sustainer 3, a 63-year-old divorced Black woman with breast cancer, takes stock of the emotional resources of her loved ones, revealing facts to some members of her family while withholding information from others.

> The baby daughter is the strongest of the three. You always have one that you know is going to be stronger. She's the one that's going to have to carry us through this, so she's the one that I can tell everything to. Now my 23-year-old grandson, I haven't really sat down and talked to him about how serious, 'cause he's too close to me, you know, that kind of thing. He's like my baby. I worry about how much he can take. I've had him since he was 10 days old, and, I guess I'm not ready to tell him the extent of it. He realizes I'm sick, but not how sick.

Negotiating social support. Sustainers prefer social support that both recognizes their need for control over their lives while insuring help in time of need. For sustainers, negotiating for social support involves identifying instrumental and expressive resources in the event they are needed and attempting not to deplete them before the illness moves into its last stages. Timing is everything for sustainers as they evaluate their current need for support in light of future requirements. Preferring to stay in her own place for as long as possible, Sustainer 6, a 53-year-old Black woman with breast cancer, tires to make sure

her daughter will have the emotional stamina to care for her in the long haul.

> It's trying to figure out the right time, you know. I'm close to my children, and they are close to me. My oldest one, she has a house, and she told me that, you know, "will you come stay with us?" I said, "I don't know if its time for me to come and live with you. I want to be at home and take care of things for as long as I can." When I get so sick where I have to, then, you know, I'll go stay with them. I don't think they have to get all stressed out waiting on me now, but I think I'll need them down the road, and I want them to be strong then.

Deeply committed to the emotional well-being of her loved ones, Sustainer 3, a 63-year-old divorced Black woman with breast cancer, assumes the burden of easing the trauma of her illness for them, refraining from asking for help for as long as possible.

> I've always been concerned about my family, especially rather than what really matters to me. I've always been a worrier. And I worry about other people all the

> time, I mean, before myself. I'm always the last one. My problem is I want all my kids to be happy and that's not necessarily going to be. There are days when I find myself slipping into depression, and I'll snap out of it because of them. I don't know if that's good or bad, because I can't protect them from the emotional trauma forever. And I'm going to need them to be strong near the end. I want to go easy. I just don't want to die alone. I expect them to be my support when I'm dying. My dad, he died alone and, and I thought what a horrible way to go by yourself. I've always been around people. I've never lived by myself and I don't want to die by myself.

Unable to carry the emotional burden entirely on their own, sustainers seek social support from clinic staff. Without expectations of reciprocity, the emotional support they receive from the clinic does not create an added burden on them. Experiencing the clinic as a place of comfort, sustainers feel cared for, nurtured, and uplifted by the staff without incurring any obligations for the emotional life of the staff. Sustainer 4, a 49-year-old Black woman with breast cancer, illustrates this point.

> Everybody here is nice. Everybody here is sweet and they treat you like family. They're very easy to talk to, and they listen to you when you talk to them. They try to be like family, but really they are better than family, because I don't have to worry about how they're feeling. But I still try to be nice to them, you know, 'cause they're so nice to me.

Managing affect. A key emotional task for sustainers is controlling their affective expression so that it does not burden their loved ones. While this drive to protect others is foremost in their minds, sustainers exercise emotional restraint so that others' emotions will not become added burdens on them. Sustainer 3, a 63-year-old divorced Black woman with breast cancer, explains this point.

> I think anybody can live with cancer. The pain or the emotions are strong, but you have to get a handle on yourself. The hardest thing for me each day now is staying hyped up so they won't really feel my depression and take it on themselves. I try to stay smiley, well, I've always smiled. I got to deal with all these emotional changes daily, and theirs too. Ok, let's see what the day is going to be like for me, or who's coming today, or which one of the kids are going to be here, so I'll know how to get my mood up today to meet expectation.

In a similar manner, Sustainer 2, a 69-year-old Black woman with breast cancer, shields her daughters from distressing emotions in the hope that they, in turn, will not become an added burden on her.

> My daughters work, and they just can't be there with me all the time. They have gone their way and do what they have to do, and I have to do what I have to do, so I just feel like I just have to roll. I appreciate them and thank them for being concerned about me, but I cannot lay it on them, cry on their shoulders all the time, and I don't do that. I don't want to be sitting around crying and moaning and pitying me. Next thing you know, they'd be in as bad shape as me, and then I'd really have a load on my hands. It's better I keep my feelings in control so my children's feelings don't get out of control.

Similarly, Sustainer 6, a 53-year-old Black woman with breast cancer, tries to hold everything together emotionally for herself and her mentally ill daughter.

> I decided to feel positive, and that's the way I keep myself calm for her, because if she sees me break down, then that's it for her. It might be a big blow up, and I do not want to deal with that while I'm worn down by the chemo. If things get out of control, I might have to put her in an institution, and she's never been in one. It would be hard for me to see her go there, because we just take care of each other. So, either way, you know, it's not an easy thing to get through.

Acutely aware of the effect of emotional outbursts on others, Sustainer 1, a 48-year-old White man with lung cancer, assumes the added burden of not upsetting others.

> I got a lot of people upset cause I've been crying and all but, you know, I just can't help it. I'm trying not to do much crying around them so they won't stay away. I'm trying to keep all my emotions to myself. I just smile and laugh around them.

Attempting to manage the interactional demands of terminal illness, sustainers employ a reactive approach to adversity, going into battle against the debilitating effects of the disease and the unsettling impact of others' emotions. Aware of their need for help but unwilling to deplete their supply of emotional resources early in the illness trajectory, sustainers try to maintain the emotional status quo for as long as they can. Like their interdependent counterparts, shapers offer a contrasting view of how the terminally ill try to manage their social worlds without assuming the added burden that reciprocity entails.

The Shaper Type

Representing 27% (*n* = 9) of the sample, shapers are the largest of the categories. Characterized by an overrepresentation of Blacks and women and underrepresentation of married subjects, shapers reflect the demographic make-up of the independent mode. Compared to the 27% of the sample who are currently married, the shaper category does not contain any married subjects. While Blacks constitute 70% of the sample, they account for 89% of the shapers. Compared to 70% of the total participants, 74% of shapers have been diagnosed within 18 months of the start of the study. At the time of this writing, 45% of the shapers have passed away, compared to 61% of the sample with two surviving subjects under hospice care for end-stage cancer.

Unlike sustainers, who work to maintain the emotional status quo, shapers try to to restructure the emotional patterns of their relationships. Acknowledging that changes in their health status requires a realignment of the give and take in their relationships, shapers take charge of the situation, directing others in discerning how best to deal with practical day-to-day concerns and long-term issues. Shapers appear to want to mold the way that others perceive the situation, relying heavily on their ability to acquire and share information about their illness. Viewing themselves as capable of acting autonomously, shapers are also aware that the time will come when they will need to accept help from others. As they gradually shift the responsibility for their physical, psychological, and spiritual well-being to others, shapers maintain control of the interpersonal dynamic, the definition of the situation, and the emotional tone of the setting.

While sustainers engage cancer by attempting to hold their own in the face of predictable decline, shapers carve out an approach to terminal illness that is uplifting and open-ended. Believing in the importance of positive thoughts and feelings, shapers prefer to focus on possibilities for healing rather than on probabilities for dying. Shapers cope with terminal illness by making sense out of adversity and finding meaning in suffering. As a case in point, Shaper 4, a 64-year-old White woman with breast cancer, interprets her condition in light of a deeper awareness of the meaning of everyday life and a greater appreciation for the simple joys of living.

> [What's it like for you as a person to have cancer?] I want to say I thank God for it. We go along at life, and I get up this morning and I don't really have anything, and then all of a sudden you have something. It's like possessing a diamond and not seeing the sparkles. As you turn the page of a book, you anticipate. So, my anticipation is turning the pages of that book. I never thought I could ride a horse, but I did, and I'm going to do it again. I've done these all along, but now they're taking a new meaning. I think if people would realize how much there is to do out there, they would appreciate life more. There's so many possibilities that it's silly just to sit back and say, well, I'll just wait for it. I do more now than before, because these things have meaning now.

Shapers actively seek and acquire facts about their medical conditions and use the information to frame the terminal illness experience for themselves and others. Believing in their ability to deal with the truth, shapers want to know about their prognosis so they can develop a plan of action. Unlike sustainers, who selectively shield loved ones from the full extent of the illness, shapers do not try to hide information about their situations from others. Confronting the illness head-on and giving her loved ones the details of her medical condition, Shaper 6, a 46-year-old Black woman with cervical cancer, feels that facing the facts and sharing them with others enhances their capacity to attend to her needs.

> I told all the kids at the same time. I didn't try to hide it from them. I called them down to the house, and had them all at the house, and then I told them how it was going to be. They didn't react. They really didn't say anything. They all waited and called, and the oldest one called the younger one who is with me now. They called and they talked to each other, and, decided they was going to take care of me the way I wanted it done, and they have. The one who's 25, she's pregnant, so she's been there through the whole thing, the doctor visits and all, she's been there. My daughters are wonderful. So, I think they do pretty good.

Negotiating social support. For shapers, negotiating for social support involves educating others about the illness and instructing them in appropriate ways to think and feel about it. Unlike sustainers, who feel obligated to selectively manage information to minimize the impact of terminal illness on their loved ones, shapers believe that family and friends should learn as much as they can about terminal illness so they can function as advocates and allies. Shaper 7, a 54-year-old Black woman with breast cancer, points out that providing facts to family members is an important tool for eliciting support.

> I open up and talk about things. Cancer is a word that can make people afraid because, you know, people have I call 'em misconceptions about things. Most of my children are grown and old enough to understand the truth, but even my 10-year-old, he seems to understand things. He might now understand all things, but I sat down to talk to him and told him what was what. You should talk about things especially with your family and children. Otherwise, how else will they know how to help you?

In the shaper scheme of things, social support does not emerge from the illness experience alone, but constitutes an enduring quality of the "give-and-take" dynamic of relationships with others. Affirming the help of her family and friends while recalling all she's done for them, Shaper 4, a 64-year-old White woman, highlights the reciprocal nature of social support.

> I like to talk to people, and I have good people around me. They support me every way they can. They're giving themselves and to me that means a lot 'cause in giving, you receive. My children have been so attentive. I'm eating that up. I really am. And they seem to be enjoying it too. I've always done what I could for them, and they've always helped me out with little things here and there. It's about time they stepped up in a big way. It's my turn now to be receiving.

Because of their emphasis on sharing information, shapers do not differentiate between instrumental and expressive support. Shaper 3, a 67-year-old Black man with leukemia, explains that when others seek out information on his behalf he interprets it as an expression of care and love.

> I'm going to go to those support meetings they have here, 'cause if I sit in, I'll learn about my condition. If there's something I don't know, I call my daughter and I ask her to find out things for me, and when she does, it's like she's showing me how much she cares. She knows I feel better when I know what's going on.

Finding comfort in the ways others care for him, Shaper 8, a 54-year-old Black man with lymphoma, explains how instrumental and expressive support are inseparable.

> My girlfriend, she listens to me to whatever I have to say. She'll find out things for me and give me her input, and then she'll tell me everything is going to be okay. I get a lot of comfort, too, when I come over to the hospital for my check up, for my treatments. I get a lot of comfort out of the way, you know, they really take care of me and let me know what's what.

Managing affect. Unlike sustainers, who restrain their expression of affect to keep from generating unwanted emotions in others, shapers boldly exude expressive sentiment as a model for loved ones to emulate. For shapers, affective expression is purposive and intentional, emanating from a well-thought-out plan for managing the illness experience. As part of a process of coping with terminal illness, shapers make decisions about what emotions they want to generate in themselves and elicit from others. The dynamics of this process are apparent in the life of Shaper 5, a 23-year-old single Black woman with lymphoma.

> We've never had nothing like this before. My grand mamas are alive, my grand papas all of them, all of my great grand mamas, my great aunts all of them they still living, and none of them have had nothing, you know, really major. So none of us know what to be feeling. Sometimes I be tired but I don't feel like I'm sick. I try to keep from having a sick way about me. I've got to show them the way or they'll be saying "oh, you sick, you need to do this and you need to do that, don't be running around too much. You sick and you need to sit down." So, I told myself, I ain't going to have that feeling of sickness be the boss of the house.

Adopting a posture of emotional hardiness, shapers try to replicate it in loved ones so they can function as allies rather than adversaries. Shaper 1, a 54-year-old Black woman with breast cancer, finds that without her emotional direction her children tend to function as barriers in her crusade to live life fully.

> My daughters don't understand why I'm so tough. They think I should be down in the dumps. I try to make them understand I can't let this cancer get the best of any of us. I tell them people should have an upbeat attitude and not a negative one, so the disease don't go negative. I want them to feel that way too.

Believing emotions are contagious, Shaper 9, a 51-year-old Black woman with breast cancer, tries to infect family and friends with her emotional tenacity.

> I'm the only one still alive from my chemo group. I'm a person who never gives up, and my family is amazed by my strong spirit. I believe our spirits wear off on each other. I told them there would be no weak spirits trying to get me down. I don't like to be treated like I'm delicate, because if people treat me with a fine white glove, it's not good for my spirit. Don't treat me like a piece of porcelain that's about to break. People don't treat me that way 'cause I tell them how I feel.

Similarly, Shaper 2, a 53-year-old Black woman with breast cancer, dictates an emotional response to her illness that encourages her to be strong and determined.

> I tell people if they treat me softly like a powder puff, saying "ooh, you poor thing and all," then they're going to turn around and make me wilt. People with cancer need a high spirit. You have to lift them up and encourage them. That's what I try to get people to do for me. If I'm down in the dumps, I can't make it. I tell them, don't treat me no more, you know, no less than the other person, because that makes me lose hope and spirit.

As an interactional strategy, the shaper approach to terminal illness is the larger of the interdependent types and the most prevalent in this study. Relying heavily on the individual's capacity for effective interpersonal communication, the shaper stance toward others is qualitatively different from that of the sustainers. Unlike sustainers, who try to palliate the emotions of loved ones by managing impression and sentiment, shapers try to change the way others think and feel by informing, educating, and guiding. By providing insight into another aspect of the interdependent mode of engaging terminal illness, the shaper type emerges as a distinctive stance toward the experience of incurable cancer. In conclusion, Table 4 provides a summary of the six types of interactional strategies to clarify their distinguishing characteristics and highlight the differences among them.

Table 5

Summary of Interactional Strategies

Types	Salient characteristics	Negotiating for support	Managing affect
Independent			
Resisters	highest mean age and highest death rate	discourage pity and unwanted advice	limit illness dialogue and use emotional facades of well-being.
Dismissers	highest education level lowest marriage rate highest percent male	minimize severity of illness to convince others no help is needed	detach from emotional dynamic of household
Dependent			
Relinquishers	lowest mean age and lowest education level	give lip service to others' interpretive schemes	conform to others' emotion rules even when they are a poor fit
Distressers	highest divorce rates and shortest disease trajectory	exaggerate severity of illness to elicit help and comfort	generate painful affect in others and elicit excess emotionality
Interdependent			
Sustainers	highest percent female and longest disease trajectory	engage illness with fighting spirit and refrain from depleting resources	customize disclosure to fit others' ability to cope to maintain emotional status quo
Shapers	highest rate of single-parenting and lowest death rate	Focus on possibilities and educate others to be advocates and allies	generate positive affect by framing illness as an opportunity for growth

CHAPTER 5

DISCUSSION

A diagnosis of terminal illness marks both an ending and a beginning in the life of a cancer patient. On the most basic level, it corresponds with the end of life as he or she knows it and ushers in the final stages of his or her time on earth. On another level, it brings closure to the inchoate phase of the illness career and marks the beginning of death awareness and the existential crisis accompanying it. As patients attempt to adjust to the physical changes and psychosocial demands of terminal illness, they experience a sense of burden and loss. Of all the burdens of terminal illness, perhaps the most difficult is the stress of managing the emotions that emerge in the social support process. In his examination of caregiver burden among family members of the mentally ill, Karp (2001) describes the emotional conflict caregivers experience when their feelings seem inappropriate.

> It is not surprising that severe illness makes particularly exhausting emotional demands on healthy family members. In one survey, 48.1 percent of the sample named serious illness, suicide, or death of a loved one as generating emotions other than what respondents thought they "ought" to feel. As difficult as it is to manage emotions in caring for a physically ill person, efforts to negotiate appropriate emotions are still more arduous in dealing with a mentally ill person. (pp. 71-72)

Although the social support literature documents the emotional difficulties caregivers experience, there is little research on the emotional costs of caregiving for patients. Unlike the mentally ill in Karp's study, whose affective disorders render them incapable of feeling appropriate emotions, the terminally ill are subject to feeling rules they often experience as burdensome. While the emotional costs of being terminally ill can differ from patient to patient due to the variations in the interpersonal dynamics of caregiving arrangements and the coping strategies used to manage them, the effect on the well-being of patients is the same. At a time when patients can least afford to expend physical or emotional energy, the terminally ill feel obligated both to generate appropriate feelings as well as elicit them from others. In her study of chronic illness, Charmaz (1991) finds that patients do not passively accept all the demands that are made on them but, instead, make choices about what relational burdens they must incur as a cost of care. In a discussion of the dynamic of "pulling in," Charmaz (1991) describes how patients assume an active stance on their own behalf to minimize claims others have on them and to maximize their ability to fulfill obligations they cannot avoid.

> Immersion in illness shrinks social worlds. It forces people to pull into their inner circle while pulling away from others. They must try to protect themselves and to keep some control over their lives. They have little strength for anything beyond illness. Pulling in is a taken-for-granted adaptation to serious illness. Pulling in permits ill people and their caregivers to tighten the boundaries of their lives, and to struggle with the exigencies of illness. Usually, people tighten their essential relationships and loosen problematic bonds and causal ties. . . . [As one patient explained], she felt that she could not afford the time, physical energy and psychic space to handle anything more. (pp. 81-82)

Although the evidence is inconclusive, some research findings suggest that the emotional costs of terminal illness are greater among poor and minority populations where emotion-focused coping strategies dominate over problem-focused ones (Thoits, 1995). In research on coping, Lazarus and Folkman (1984) found that individuals often employ more than one strategy in dealing with stressful events, because stress is associated with both the situation itself and the emotions which accompany it. While problem-focused coping attempts to minimize situational stress when demands seem controllable, emotion-focused strategies try to moderate or modify emotional reactions to situations where demands are perceived as uncontrollable. As Thoits (1995) explains,

> Coping researchers generally expect problem-focused coping to be more beneficial for well-being than emotion-focused coping. Despite this belief, there is no clear consensus in the literature regarding which coping strategies are most efficacious in reducing psychological stress or ill health. . . . [Thus] a key question for sociologists is whether coping techniques and/or coping styles are distributed unequally by social status. . . . [While] racial and socioeconomic differences have rarely been examined, some studies indicate that highly educated individuals are more likely to use or prefer problem-focused strategies. . . . In general, social status differences in coping styles and in situational coping responses require further exploration. (pp. 61-62)

For the respondents in this study, attempts to deal with the often overwhelming emotions accompanying terminal illness extend beyond their own distressing feelings to include the feelings of others. The emotional needs of family members are an issue not only because patients worry about the impact of the diagnosis on their loved ones, but also because they are concerned about the effect of others' emotions on them. One of the most remarkable insights to emerge from this research concerns the reciprocal nature of emotional labor between the terminally ill poor and their caregivers. Unlike accounts in the literature which give the impression that the burden of managing emotions is born by caregivers alone, patients in this study report investing a great deal of time and energy in managing the emotions of others. Indeed, the notion of reciprocity, in all of its forms, is key to understanding the coping strategies patients employ in their attempts to manage the affective dimension of the terminal illness experience.

The Notion of Reciprocity

In its most general form, reciprocity refers to giving and taking without the use of money and involves exchange of goods and services between people who are bound in nonmarket, nonhierarchical relationships with one another. While reciprocal exchanges serve the economic function of redistributing goods or services, they also strengthen social bonds and maintain social order. Governed by the norm of reciprocity, exchanges require, at the very least, that individuals repay gifts by helping and not hurting those who have assisted them. In the literature on aging, Quadagno's (1999) discussion of the "norm of beneficence" addresses how individuals develop a sense of entitlement over the life course as they accrue "social credits" by doing good to others. As Gouldner (1960, p.171) notes, "gifts have to be repaid . . . [as] they constitute a debt, and until discharged, individuals involved are in a state of imbalance." Based on numerous ethnographic accounts of exchange relationships in primitive societies, social anthropologists have identified three ideal types of reciprocity: generalized reciprocity, balanced reciprocity, and negative reciprocity. Generalized reciprocity involves giving gifts without the expectation of immediate repayment. As Ember and Ember (1973, p. 123) explain, generalized reciprocity is based on the unspoken premise that "what one gives is eventually returned, although not necessarily right away or by the same person or involving the same object or service originally given." In the systems where generalized reciprocity is the norm, the distribution of goods and services evens out in the long run. Balanced reciprocity, on the other hand, requires repayment in kind over the short term. Finally, unlike generalized and balanced reciprocity, which are based on mutual interests, negative reciprocity operates out of self-interest, involving attempts to take advantage of another by engaging in uneven exchanges.

According to Sahlins (1965), the three types of reciprocity can be conceptualized as a continuum of exchange based on social distance. Whereas generalized reciprocity guides the exchanges between family and close friends, balanced reciprocity regulates the exchanges between peers who are not closely related. Finally, negative reciprocity is utilized against strangers and enemies. As Bohannan (1966, p. 232) explains, "the most vivid systems of reciprocity are those based on kinship obligations . . . [where] the exchange does not constitute the relationship, but rather is part of the behavior that gives it content." In ethnographic accounts of kinship groups in primitive societies, examples of reciprocity range from offering hospitality, providing mutual aid, exchanging token gifts, sharing goods, and extending offers of generosity (Sahlins, 1968, pp. 82-83). Social anthropologists have documented the fact that in primitive cultures, highly expressive, ceremonial exchanges between kinship and tribal groups serve to enhance prestige, save face, and maintain social harmony (Bohannan, 1966). In industrialized societies, where money in its many forms is the dominant medium of exchange, nonmonetary exchange is not as common. However, as a means of survival and source of reputation enhancement, such practices are fundamental elements of the lives of the poor. As Stack (1974) notes,

> [In studying The Flats], I found extensive networks of kin and friends supporting, reinforcing each other— devising schemes for self-help, strategies for survival in a community of severe economic deprivation. . . . Trading in The Flats generally refers to an object or service offered with the intent of obliging. An object given or traded represents a possession, a pledge, a loan, a trust, a bank account— given on the condition that something will be returned, that the giver can draw on the account, and that the initiator of the trade gains prerogatives in taking what he or she needs from the receiver. . . . The trading of goods and services among the poor in complex industrial societies bears a striking resemblance to patterns of exchange organized around reciprocal gift giving in non-Western societies. (pp. 28-29, 34)

Because reciprocal transactions among kin are at least "putatively altruistic," the obligation to repay in kind is predicated upon the recipients' capacity to do so (Sahlins, 1968, p. 82). As Sahlins (pp. 82-83) notes, "the obligation to reciprocate is diffuse: when necessary to the donor and /or possible for the recipient . . . there are people— the widowed, the old, the impaired— who in the fullness of time remain incapable of helping themselves or others." From the sociological perspective, the norm of reciprocity is a fundamental element of the social bonds that hold society together. While the exemption from reciprocity granted to kin unable to reciprocate minimizes the obligation to repay in kind, it does not release individuals from social indebtedness in the form of gratitude. In his examination of the interpersonal component of the gift process, George Simmel (in Wolff, 1950, p. 389), discusses the sociological function of giving.

> Giving, itself, is one of the strongest sociological functions. Without constant giving and taking within society— outside of exchange, too— society would not come about. For, giving is by no means only a simple effect that one individual has on another: it is precisely what is required of all sociological functions, namely interaction. By either accepting or rejecting the gift, the receiver has a highly specific effect on the giver. The manner of his acceptance, gratefully or ungratefully, having expected the gift or being surprised by it, being satisfied or dissatisfied, elevated or humiliated--all this keenly acts upon the giver. . . . Every act of giving is thus, an interaction between giver and receiver, [and] gratitude emerges as the motive which, for inner reasons, effects the return of a benefit where there is no external necessity for it. (p. 389)

While gratitude is an essentially "irredeemable commodity" (p. 389) holding its claim on both rich and poor, healthy and sick, alike, the burden of sustaining gratitude rests heaviest upon those who will never be able to reciprocate. Among the terminally ill poor, feelings of gratitude can become burdensome, compelling them to cash in on other emotions as payment for their debts. While there are emotional costs of relating for all social classes, these costs may be secondary to other costs for the affluent who can afford to repay their emotional debts with material goods. In the absence of other resources, emotional currency becomes more salient. The burden is even greater for the terminally ill poor, who have no hope of reciprocating in the future for assistance received today. While the wealthy may reciprocate through survivors' life insurance benefits or by bequeathing a generous portion of their estate to caregivers, individuals in less privileged economic situations are not in a position to provide such monetary compensation. For members of less advantaged groups, an emotional bank account becomes the resource of primary importance in defining their interactions with others and shaping their response to terminal illness. When indebted to others for expressive and instrumental support, one way for them to show gratitude and alleviate the burden of indebtedness is to engage in "emotion work" that enhances caregiver esteem and promotes their well-being. For the terminally ill, however, the emotional resources needed to accomplish this task may be difficult to access and costly to use.

The Sociology of Emotions

The interpretive framework of the sociology of emotions offers a way of making sense of the coping strategies patients employ as they attempt to manage and direct the affective dimension of terminal illness. It also provides the means of acquiring deeper insight into the emotional costs patients sustain in the process. Just as the guidelines for appropriate behavior are context sensitive and situationally enforced, the rules for experiencing emotions and expressing affect are culturally patterned and socially controlled. Because emotions are socially constructed and culturally sanctioned, affective expression is more than just a biological or psychological response to stimuli. Indeed, the process of generating emotions is essentially an interactive one in which actors first interpret others' expectations of them and then elicit and manifest corresponding feelings. Through the work of Arlie Hochschild (1983) on the sociology of emotions, there is renewed interest among sociologists in how emotions are generated in interpersonal encounters to achieve desired ends. As Marshall (1996) notes,

> Although a concern with emotion is present in much early sociology (for example in the work of C. H. Cooley), the sociological study of emotions emerged as a distinctive subfield within the discipline during the 1970s, in part at, least, as a

> self-conscious response to a sociology that (in the eyes of some) had become overly concerned with the cognitive and rational. It examines such emotions as shame and pride, love and hate, awe and wonder, boredom and melancholy, and asks questions about how these are culturally patterned, experienced, acquired, transformed, managed in daily life, and legitimated through accounts. At its most general, the speciality examines the links between feelings, on the one hand, and cultures, structures, and interactions on the other. (p. 148)

In her study of the airline industry, Hochschild (1983) found that, as part of their job, attendants engage in emotional labor by producing feelings within themselves that enhance a sense of well-being among the customers. In order to conform to the industry mandates about required feelings, stewardesses follow "feeling rules" that not only require them to project images of friendliness and elation as part of their jobs, but also to genuinely experience those emotions. As Hochschild (p. 7) notes, this commodification of affect carries with it an unintended cost of doing one's job: "the worker can become estranged or alienated from an aspect of self--either the body or the margins of the soul—that is *used* to do the work." [emphasis in original]

The notion of emotions as tools people use to achieve desired ends is not a novel idea. Human beings by their very nature have the capacity to use their emotions to manipulate others, gain advantage, and control the affective tone of relationships. While there have always been rules of social exchange designating appropriate affective expression and requiring external conformity, such rules target external behavior and do not demand work of the heart. For example, when visiting a friend in the hospital, while it is appropriate, as a condition of friendship, to extend to them sentiments of concern and compassion, it is not necessary to actually feel that way, because the gift is in the gesture and not in the actual emotion. As Hochschild (1983) notes,

> All of us try to feel, and pretend to feel, but we seldom do so alone. Most often we do it when we exchange gestures or signs of feelings with others. Taken together, emotion work, feelings rules, and interpersonal exchange make up our

> primary emotional system. ***We bow to each other not only from the waist but from the heart.*** Feelings rules set out what is owed in gestures of exchange between people. (p. 78) [emphasis added]

The Emotional Worlds of the Poor

A question facing sociologists working in the field of emotions concerns the relationship between social status and emotional expressiveness on the one hand, and social status and emotional generation on the other. While social scientists generally assume that the poor experience more difficulty in postponing emotional gratification and restraining emotional expression, there are those who dispute these claims, maintaining that a life of poverty actually requires more restraint than a life of affluence (Rubin, 1976, p. 75). As I see it, however, the real question concerns the existence of a way of thinking and feeling about reality that is peculiar to the poor. Does the experience of living in poverty generate a uniform set of emotions that constitutes a world of feeling that is substantively different from the affective worlds of the more affluent? While I do not pretend to have the data needed to even begin to answer such a question, I would like to suggest that a life of poverty functions as a screen through which emotional stimuli are experienced and perceived. If this is the case, it may be possible to speak in the most general terms about the emotional world of the poor and to consider how the coping strategies which emerge from it provide us with a deeper understanding of the inner life of those who are socially and economically disadvantaged.

Ethnographic accounts of the interpersonal dynamics in poor and minority communities provide a backdoor into the emotional life of the poor. In her study of working-class white families, Rubin (1976, p. 55) found that the absence of financial success often shapes an emotional milieu characterized by feelings of low self-worth and manifested in men's violent expressions of "generalized and free-floating anger." Among the working poor, anger and violence erupt most frequently in domestic settings where conflict over financial and child-rearing issues generates explosive feelings of frustration, betrayal, and jealousy that intrude into the marital relationship. The emotional burden of keeping the peace between husband and wife is shouldered almost exclusively by women. According to Hochschild (1983, p. 163), in the domestic sphere and in the workplace alike, women who lack other resources "make a resource out of feeling and offer it to men as a gift in return for the more material resources they lack."

In her account of marriage among the working-class poor, Rubin (1976) finds that women are often more willing to trade emotional well-being for the promise of financial security, as elusive as it may be. The stigma of remaining single can compel poor White women to enter into marital relationships in which the burden of emotional labor rests on their shoulders. Socialized into images of manhood minimizing the need for affective expressiveness, working-class White men feel uncomfortable with emotional intimacy and fail to attend to the emotional needs of their spouses.

> This is the dilemma of modern marriage— experienced at all class levels but, with particular acuteness among the working-class families I met. For once marriage is conceived of as more than an economic arrangement— that is, one in which the emotional needs of the individual are attended to and met— the role segregation of and the consequently widely divergent socialization patterns for women and men become clearly dysfunctional. . . . They are products of a disjunction between thought and feeling, between emotionality and rationality that lies deep in Western culture. . . . When they try to talk, she relies heavily on the only tools she has [and] becomes progressively more emotional and expressive. . . [while] he gets progressively more rational— determinedly reasonable. She cries to him to attend to her feelings, her pain. He tells her . . . [that] she's just being emotional. That clench-teethed reasonableness invalidates her feelings, leaving her sometimes frightened. (pp. 116-117)

Hochschild's (1983, p. 173) notion of the "doctrine of feelings" has a particular salience for understanding the emotional world of the poor, because "the lower [someone's] status, the more [their] manner of seeing and feeling is subject to being discredited, and the less believable it becomes." Whether it be a working-class husband pulling rank to minimize the feelings of his spouse or a highly educated physician assuming a patronizing stance toward the emotional expressiveness of a low-SES patient, the legitimacy accorded to the emotional worlds of the middle and upper classes is denied to the poor. As Hochschild (1983) notes,

> An "irrational" feeling is the twin of an invalidated perception. A person of lower status has a weaker claim to the right to define what is going on; so less trust is placed in her judgments; and less respect is accorded to what she feels. Relatively speaking, it more often becomes the burden of women, as with other lower status persons, to uphold a minority viewpoint, a discredited opinion. (p. 173)

In an examination of unemployment among the new urban poor, Wilson (1997, pp. 76-77) notes how self-doubt translates into problems of self-efficacy that manifest themselves as feelings of despondence, discouragement, and pessimism. To overcome feelings of cynicism and powerlessness, friendship networks among unemployed Black men traditionally are nurtured and sustained by a romanticized sense of loyalty. As Liebow (1967) notes,

> Since much of the cooperation between friends centers around the basic prerequisites of daily living, friends are of special importance to one's sense of physical and emotional security. The more friends one has or believes himself to have, and the deeper he holds these friendships to be, the greater his self-esteem and the greater the esteem for himself he thinks he sees in the eyes of others. The pursuit of security and self-esteem push him to romanticize his perception of his friends and friendships. . . . He wants to believe that his friendships reach back into the distant past and have an unlimited future; that he knows and is known by his friends intimately; that they can trust one another implicitly, and their loyalties to one another are almost unbounded. . . . But friendship does not often stand up well to the stress of crisis or conflict of interest, when demands tend to be heaviest and most insistent. (pp. 176, 180)

Ethnographic research on family norms of inner-city Black neighborhoods from the Urban Poverty and Family Life Survey (Wilson, 1987) found that feelings of hostility and suspicion between men and women predispose persons of one gender to write off those of the other gender as deficient in the emotional skills necessary for sustaining a relationship. While Black men are emotionally inclined to experience Black women as demanding and quarrelsome, Black women are equally prepared to experience Black men as essentially unreliable and virtually incapable of being faithful to one woman. As Wilson (1997) describes,

> Relationships between inner-city Black men and women . . . are often fractious and antagonistic. Inner city Black women routinely say that they distrust men and feel strongly that Black men lack dedication to their families. They argue that Black males are hopeless as either husbands and fathers and that more of their time is spent on the streets than at home. . . . The women in the inner city tend to believe that Black men get involved with women mainly to obtain sex or money, and that once these goals are achieved, women are usually discarded. . . . There is widespread feeling among women in the inner city that Black males have relationships with more than one female at a time. . . . Males especially feel peer pressure to be sexually active. They said that the members of their peer networks brag about their sexual encounters and that they feel obligated to reveal their own sexual exploits. . . . Whereas women blame men for the poor gender relationships, men maintain that it is the women who are troublesome. The men complain that it is not easy to deal with the women's suspicions about their behavior and intentions. They also feel that women are especially attracted by material resources and that is therefore difficult to find women who are supportive of partners with a low living standard. (pp. 98-99)

In a similar vein, Stack (1974) identifies distrust as a primary emotion in poor Black communities, where it permeates interpersonal relationships and shapes behavior both within and without the kinship group. In order to compensate for the absence of trust in exchange relations, the poor acquire "an adaptive style of behavior" where they "control, manipulate, and exploit others" (Stack, p. 39). In addition, the emotional ties that are needed to sustain exchange relations within kinship groups are cemented by sentiments of magnanimity and sacrifice expressed in "exaggerated accounts" of assistance and aid reminiscent of the extravagant exchanges of goods in archaic cultures.

> Social relationships between kin who have consistently traded material and cultural support over the years reveal feelings of both generosity and martyrdom. Long-term interactions, especially between female kin, sometimes become highly competitive and aggressive. At family gatherings or at a family picnic it is not unusual to see an exaggerated performance by someone, bragging about how much he has done for a particular relative . . . the performer often combines statements of his generosity with great claims of sacrifice. (Stack, p.38)

The Emotional Costs of Coping

We can think of the emotion work of the terminally ill poor as a form of "shadow labor" (Hochschild, 1983) because the burden that necessitates it and the effort it requires remain virtually unrecognized and unacknowledged. Bearing the hidden costs of caregiving relationships, the terminally ill poor not only have to cope with issues of financial stress, physical pain, and existential loss, but also must deal with troubling concerns over the emotional dynamics of their social settings. A diagnosis of cancer can wreak havoc in the emotional lives of poor families, in which members often have a tenuous hold on one another's well-being. Holding body and soul together in times of crisis is no easy task for the poor, but when serious illness weakens their hold on stability, it is easy to lose one's grasp and go off the deep end. Fear of losing control of emotions dominates the narratives of the terminally ill poor who worry as much about others' emotional stability as they do their own. Because life's balance is threatened at every turn by forces and events outside of their control, the terminally ill poor learn to be adept at managing the emotional dynamics of their social worlds. However, like all forms of emotional labor, the costs of emotion management has the potential to outweigh its benefits.

The emotional costs of independence. As a way of coping with cancer, the strategies used by the independent types rely heavily on their capacity to remain self-sufficient and autonomous in the face of life-threatening illness. Fearing the capriciousness of others' emotions, independent types shield themselves by resisting the overtures of others. This is no easy task, because serious illness, by its very nature, compels others to take notice and offer assistance. However, an examination of the emotional worlds of the independent types makes it easier to understand why a diagnosis of terminal illness sets in motion a process in which patients dismiss the credibility of others. It also provides a plausible explanation of why they perceive social support as burdensome and are willing to invest their store of emotional energy in resisting those who attempt to assist them.

As a group, the independent types are disproportionately single, Black, and male. Ethnographic research (Anderson, 1990; Liebow, 1967; Wilson, 1997) on the social worlds of low-SES Blacks offers a view of both the social organization shaping the contours of their community lives and the cultural sensibilities informing the stuff of their emotional worlds. Poor Black men, in particular, are depicted in ethnographic research as "footloose and fancy free," preferring the comraderie of the street corner to the comforts of home and family. Their relationships with women who make claims on their emotions or their paychecks are strained, at best, and outright hostile, at worse. Relying heavily on the mostly symbolic support of peers, poor Black men operate out of emotional worlds filled with feelings of mistrust of others and cynicism about their motives. Discouraged by their lack of financial success, they often aggrandize the size of their social networks and exaggerate their interpersonal and sexual skills, presenting a facade of intimacy in peer associations and sexual relationships.

While women are underrepresented in the independent category, those who fit the criteria of self-reliance and self-sufficiency have achieved a degree of economic independence that is rarely seen among low-SES women. Unlike the majority of the women in this study, the female independent types are purchasing homes, or already own them, and do not engage in the type of barter for goods and services that is commonly seen among their peers. For such women, relationships with men do not play a crucial role in their current lives, and female-dominated social support networks are seen as bothersome and intrusive. Most telling of all, however, the women in the independent category tend to embellish the stories of their lives with accounts of rugged individualism atypical of the other women in this study.

For the independent types, social support is a not only an emotional burden they are not equipped to handle, but also a threat to the very way the self is experienced and expressed. The notion of "self" is critical here not only because it is the defining element of personal identity, but also because it is the reservoir of emotion and the object of feeling rules. In her theory of ethics and emotions, Margolis (1998), develops a typology of images of the self that have emerged through history. Her description of the "exchanger" resonates with my conceptualization of the independent types.

> [The "exchanger" type is] a rational calculator balancing the quid pro quos of life. The belief that nobody gets or gives anything except in exchange for something else permeates this view of human nature and human behavior. (p. 3) The exchanger image many Americans hold includes the idea that humans are naturally self-interested and competitive. In this image, the self strives for emotional control . . . [and sees itself] as free from obligations. (pp. 6 & 8) This orientation sees itself as alienable and fungible— that is, it treats itself as a commodity, [and] it is designed for human relationships that can be more fleeting than sand sculptures. (p. 40)

Independent types protect the self from the emotional traumas of terminal illness by disassociating themselves from its proximate and ultimate consequences. Because life-threatening illness is an occasion when others can intrude into areas of life usually bounded by the norms of privacy, independent types do everything they can to hide the severity of their condition from others. Appearing to deny the reality of the diagnosis and its implications for their well-being, independent types often present an image of nonchalance to disguise the seriousness of the situation. The intent here is not one of deviousness or deceit, but rather one of self-preservation. The coherence of the self is at stake, not only because terminal illness threatens the continuity of the self through time, but also because it opens the door to unsolicited acts of compassion requiring emotional reciprocity. Rather than accept the gift and return it in kind, independent types run for their lives to avoid the burden of emotional embeddedness and indebtedness. For independent types, accepting the gift of others' support necessitates a radical change in orientation at the very core of the self. As arduous as that would be, surely it is no more strenuous than the task of resisting others' unrelenting offers of assistance and dismissing their unsolicited interpretations of the situation.

Facing the rigors of terminal illness alone is no easy task, even when attempts are made to minimize its impact and downplay its power to cause harm. Even the most die-hard independent types experience moments of harsh awakening when their facades of invulnerability crack and the awful truth of their situation intrudes into their consciousness. At times like that, the superficial image of strength the world perceives does not reflect the overwhelming fear and turmoil within. The emotion work involved in hiding one's feelings is child's play, however, compared to the "deep acting" (Hochschild, 1983) that is needed for patients to evoke within themselves emotions corresponding to their care-free demeanor. For most of the independent types, the emotional labor of deep acting is only possible in the context of religion. Images of an all-knowing, all-powerful supreme being evoke feelings of invincibility. Because God represents a source of social support not requiring reciprocation, independent types do not experience religion as burdensome. Indeed, for the independent types in this study religion is the lynchpin holding together their inner and outer worlds and enabling them to feel everything is under control and all is well.

From an applied perspective, it is important to consider the idea that religiously referenced interventions could offer the best opportunities to provide social support to terminally ill patients fitting the profile of the independent types. The notion of religion-based interventions does not imply that the institutional church should be a key piece of the strategies that social service and medical personnel employ in their work with the terminally ill. Indeed, many independent types are tangentially connected to their church communities and do not desire pastoral care from a minister or chaplain. Rather, the religious perspective articulated by the independent types should be the basis of the interpretive schemes health care professionals employ in framing the illness experience for both patients and their families. When social support actually fits the patients' needs, it can alleviate emotional burdens rather than create new ones. Having family members on the same page as the patient is especially important for the independent types, because it reduces the need for patients to expend a lot of emotional resources resisting others and dismissing their input.

Practically speaking, how might such psychosocial interventions look in medical settings? Because independent types are often labeled as being "in denial," effective interventions must begin with an acknowledgment of the legitimacy of their stance toward illness. Because patients engage in coping strategies that suit their psychosocial profiles and reflect how they experience themselves, when health care personnel disavow the independent approach to illness, they are, in effect, rejecting the patients who utilize it. While acceptance does not imply agreement, it provides a means of entering the emotional worlds of patients and offers health care personnel an opportunity to shape those worlds in ways that enhance psychosocial well-being.

Because the language of religion resonates with how independent types navigate their worlds, the use of religious terminology to frame the terminal illness experience is a way for medical personnel to establish rapport with patients. Those working in medical settings with the terminally ill poor need to be medically bilingual. Not only must they speak the language of medicine with a sensitivity that appreciates the subtleties of cultural meaning accompanying many of the terms they use, health care personnel must also articulate the language of the heart with a warmth that affirms the value of placing one's faith and hope in something outside of the scientific domain. The use of religious terminology in conversations about coping might be a good place to start.

As difficult as it may be, establishing a relationship of trust with patients in the independent category is crucial to their longterm well-being, because the time will come when physical autonomy and emotional self-sufficiency are no longer viable options. Allowing others to care for them near the end of life is a major emotional hurdle that requires some degree of preparation. Information sharing with family members is one area where independent types can begin the process of "letting go" of their need to face death alone. Yet, many independent types experience feelings of fear and betrayal when family members go behind their backs to get information from health care providers. At its most basic level, establishing trust means assuring patients in word and in deed that they are a critical piece of the health care equation and that their desire for privacy and need for control will be respected. A series of family conferences where patients are led gradually through the work of disclosure might be a way to ease them into the family network without eliciting suspicion or creating an added sense of burden. As time consuming and emotionally demanding as such an endeavor would be, it holds the possibility of freeing independent types from their self-imposed isolation and enabling them to feel more comfortable with letting others into their worlds.

The emotional costs of dependence. As a way of coping with cancer, dependent types rely heavily on their capacity to recruit a family member or friend who will take control of the terminal illness experience, moderating its impact on the patient. Dependent types not only relinquish their physical care to others, but they also assume the caregivers' affective stance toward the illness experience. For some dependent types, the emotional labor takes place on a relatively superficial level, as patients give the impression of following caregivers' emotion rules without engaging in the hard work of actually feeling the prescribed emotions. For other dependent types, however, a pre-existing emotional embeddedness with caregivers compels patients to assume caregivers' emotions. This leads to higher levels of distress for patients and creates an environment of emotional contagion that infects the caregiving process.

The dependent types are disproportionately White, with an overrepresentation of separated or divorced individuals with less than a high school education. Ethnographic research (Rubin, 1976) on the social settings of low-SES Whites reveals a stark contrast in the emotional worlds of men and women. While low-income White men follow emotion rules that negatively sanction affective expression, their female counterparts are socialized into a world where the expression of emotional sentiment is a primary means of communication. The essential incompatibility of male and female modes of engaging others can lead to emotional estrangement between the sexes, while attempts to reconcile differences and restore harmony often take place at the cost of self-alienation.

Operating under a mandate to keep feelings within expressive boundaries, low-SES White men have little experience engaging the world from an emotional perspective. When terminal illness strikes, patients are overcome with feelings of fear and sadness that overwhelm their capacity for coping. Poorly equipped to deal with the flood of emotions accompanying terminal illness and lacking the skills needed to manage them, poor White men tend to relinquish the responsibility for their feelings to others. In a process characterized by the marked absence of role negotiation, patients' mothers and sisters typically assume the burden of caregiving, while ex-wives and children remain on the margins of the terminal illness experience. Because the emotional distress is usually beyond the scope of caregivers to mediate or moderate, they too are drawn into the pain and suffering of their loved ones.

In a strange twist of fate, caregiver pain has a way of creating an added burden on patients, who feel culpable for the grief they have heaped upon loved ones. The sense of responsibility they feel for caregivers' pain leads to a distorted sense of blameworthiness and a relentless sense of guilt. This is compounded by the fact that, in many cases, the cancer can be traced to lifestyle choices related to alcohol consumption and cigarette smoking. Seeking absolution for their sins, low-SES men defer to the authority of their caregivers, feigning a submissive stance and giving lip service to their caregivers wishes. Losing the feeling of immunity once allowing them to engage in risk-taking behaviors with impunity, poor White men pay heavily in emotional currency for the security of others' care. No longer exempt from the detrimental effects of their poor health habits, dependent White men are forced to let go of the emotional frames that sustained their former lifestyles and conform to the affective expectations of their caregivers.

In a similar way, low-SES White women relinquish the definition of the situation to others and attempt to generate the emotions that caregivers dictate. In some ways they have less difficulty with this task than their male counterparts, because they are used to doing emotional labor in the home and on the job. In addition, the emotional lives of poor White women are often discredited, leaving them with doubts about the legitimacy of their feelings. Indeed, it is not uncommon for such patients to apologize for their feelings and preface their accounts of family problems with depreciating comments such as "I know it's silly to feel this way, but. . . ." As embedded as the patterns of emotional self-doubt may be among poor White women, they carry with them a heavy cost in terms of mastery and esteem. Holding others in higher regard then they hold themselves, White woman dependent types do not trust the validity of their own emotions. While "putting on" the emotions of others relieves feelings of inadequacy and provides a needed sense of control over the situation, it alienates patients from the emotional life constituting their experience of self.

In an examination of the relationship between emotion and self, Margolis (1998) describes a "cosmic" orientation toward the inner life that has relevance for our understanding of the emotional worlds of the dependent types in this study. Like distresser and relinquisher patients, Margolis' cosmic type seeks unity and connectedness in the cocoon of loved ones, failing to individuate or differentiate itself from others. As she explains,

> this self has no boundaries . . . there are boundaries neither in space, nor in time, nor even in identity. . . [leaving] no separate individual. (p. 11) What the cosmic self wants above all is an emotion, an ecstatic feeling of love that binds all . . . [and] sometimes this search leads to an intense self-absorption. (p. 98)

For the dependent types, the absence of boundaries for defining the limits of the self, combined with a tendency toward self-preoccupation, contribute to feelings of being overwhelmed by the illness experience. Looking to others to rein in out-of-control feelings, dependent types exchange one set of affective distress for another. The emotional cost of care is high, as it necessitates reconstructing one's inner life out of the affective materials supplied by another and losing oneself in another's identity. At life's end, this loss of the emotional self is especially painful, because it intersects with a diminishment of the physical self and a drawing in of the social self. Issues of personal identity are a source of suffering for the dependent types as they seek to tie together the loose ends of their lives and achieve some sense of closure. While many terminally ill patients turn to religion as a source of comfort in the face of personal disintegration, dependent types do not find solace in religious constructs designed to ease them through their deaths. For the dependent types, religion functions as an additional stressor heaping more guilt and anguish upon their already burdened souls.

From an applied perspective, the traditional approach used by hospice in home-centered care of the dying does not adequately address the complex psychosocial needs of the dependent types. The hospice focus on the role of a family member as the primary caregiver only aggravates the emotional embeddedness characterizing patients' lives. In the absence of financial resources, the terminally ill poor cannot afford to employ outside help to de-intensify the family dynamic and alleviate the sense of guilt patients feel about burdening loved ones with their care. Of all the types in this study, the patients in the dependent category could benefit the most from medical and social service interventions taking patients' care out of the home and putting it in the hands of palliative care specialists in nursing homes or in-house hospice units. Clinical settings, as well, can promote the psychosocial well-being of dependent types by providing on-site support groups to assist patients in working through their painful emotions. Family members, too, could benefit from sessions that would help them understand the emotional burdens that dependent types incur in their attempts to conform to others' expectations of them.

The hospice focus on the spiritual well-being of patients typically uses religious frames of reference. For the dependent types, many of whom do not think about death in religious terms, a visit from a chaplain evokes feelings of inadequacy and shame. For reasons too complex to unravel here, dependent types approach the ultimate issues of life and death from the perspective of a nonreligious meaning system. Instead of focusing on a transcendent God to whom they are ultimately accountable, dependent types prefer to concentrate their attention on pleasing others and eliciting positive feedback from them. For most dependent types this involves an ethic of personal responsibility in which they feel compelled to do the best they can so they don't let others down. Because dying is the ultimate form of abandonment, dependent types struggle with feelings of failure that cannot be relieved by religious platitudes. More than any other type, patients in the dependent category benefit from psychosocial interventions that enable them to restore a sense of coherence and rightness to their lives. One way to do this is to provide patients with the opportunity to "find themselves," validate their contributions to others, and achieve a sense of closure through the construction of a life-history. While this may be too time-consuming a task for medical and social service professionals, specially trained hospice volunteers could assist patients in putting together the story of their lives and, in some small way, help them affirm the value of their time on earth.

The hospice focus on the management of pain attempts to provide cancer patients with relief from suffering while enabling them to remain alert during the end-stages of their illnesses. Cases of "difficult dying" seem to be more common among the dependent types, however, who may suffer from intractable pain that is more psychosocial in nature than biological. Dependent types seem more susceptible to the somatization of painful emotions, and the presence of family members often intensifies suffering at the end of life. Feelings of fear, anxiety, and guilt interact with the physical discomfort of advanced cancer, producing unrelenting distress at the end of life. The hospice ideal of a pain-free death often misleads family members about the capacity of medical science to achieve a peaceful end for their loved ones. In many cases, "terminal sedation" is used as a last resort to alleviate suffering by putting patients in a deep coma that will help to ease them into their death. Although, some patients continue to exhibit signs of suffering that are distressing to their loved ones. There is an urgent need for research on the develop- ment of pharmacological interventions capable of managing the combination of biopsychosocial and existential suffering that dependent types may experience at the end of life.

The emotional costs of interdependence. Unlike independent and dependent types, whose stances toward others are on the extreme ends of the relational continuum, the interdependent types attempt to strike a balance between self-sufficiency and reliance on others. Tied into networks of mutual support, the interdependent types are adept at negotiating reciprocal relationships. As a category, the interdependent types are disproportionately single, Black, and female heads of intergenerational households. Ethnographic research (Stack, 1974) on the social worlds of low-SES Blacks women reveals a structure of dense social ties functioning as a kinship system. Lacking adequate financial resources to support their households alone and socialized into an emotional world where uncertainty about the future and mistrust of others reign, interdependent types create networks of mutual obligation binding them to one another and alleviating a pervasive sense of insecurity permeating their lives. These networks function like bank accounts from which individuals can draw resources in time of need. Maintaining a balance between deposits and withdrawals can be difficult at times, especially when a personal crisis intrudes and weakens an already tenuous hold on life. Overdrawing one's account puts individuals and their households in jeopardy by weakening their negotiating power in the network of reciprocity.

When terminal illness enters their lives, the interdependent types find that the most important commodity is emotional support. Because of the reciprocal nature of gift-giving relationships, interdependent types are acutely aware of the emotional costs they must sustain in the caregiving equation. By its very nature, however, terminal illness severely diminishes the capacity of patients to bargain as equal partners in the caregiving arena. Unable to reciprocate for the support they receive, yet unwilling to forgo the assistance of others, interdependent types assume the burden of managing others feelings in order to keep the emotional investment within acceptable boundaries. Strategies designed to maintain the emotional status quo for as long as possible play a major role in the coping processes of interdependent types. Such endeavors require hard work on the part of patients who expend a great deal of emotional currency ensuring that caregivers' gifts of support do not exceed patients' capacity to reciprocate. When the scale of giving is tipped in favor of the caregivers, patients lose the bargaining power they need to shape the process in ways that support their sense of self. As Margolis (1998, pp. 74, 108-109) explains, from an historical perspective, "equality or inequality of persons is one of the great divides among ideas about the self . . . [and] gifts are often used to mark boundaries of the self."

In her typology on the relationship between emotion and self, Margolis (1998) develops the notion of the "obligated self." With its emphasis on reciprocity and mutual gift-giving, the obligated self captures the essence of the interdependent type. As a social construct, the idea of the obligated self is rooted in the nurturing roles women historically assume in society and the emotional labor they traditionally employ to fulfill the requirements of those roles. As Margolis (1998, p. 10) explains "we mainly find the labor that is presumed to come from women's very nature: bearing and raising children, keeping house, *managing affective social relationships*" [emphasis added]... is the defining element of the obligated self. In this context, the obligated self is sustained by a network of reciprocal relationships in which feelings are the "motors that drive persons toward the obligations they should fulfill" (Margolis, p. 57). Constituting the bonds that keep the structure of obligations in place and shaping the boundaries of the obligatory relationships, emotions must be controlled and managed so that the system of reciprocity does not lose its hold on individuals. As Margolis (1998, p. 68) explains, the boundaries that demarcate the obligated self and the system of relationships that support it protect persons from the "sorrow [which] can result from any attempt to break the chains that tie them to family, trade, religion, and class." Perhaps the best way to understand how the obligated self functions in the life of interdependent types is to distinguish it from the other types in Margolis' scheme.

> At the extremes are the exchanger orientation, which would have us erect a boundary just around ourselves, and the cosmic orientation, which would have us break down all boundaries. Between the most narrowly drawn boundaries of the exchanger self and the boundlessness of the cosmic self are the ever more inclusively drawn boundaries of the reciprocating self, the obligated self. (p. 108)

Maintaining one's place in the system of reciprocal relations requires keeping emotions within acceptable boundaries so that "out of control feelings" do not interfere with meeting one's obligations to others. For the interdependent types, the most stressful element of the process is making sure that others' feelings do not overburden the system by requiring more emotional labor from the patients than they are able to produce. It is difficult enough for patients to manage their own feelings in the face of terminal illness, but the real challenge for the interdependent types is to moderate the feelings of caregivers. One of the major ways they engage this task is to modulate caregivers' emotions by altering their perceptions of the severity of the situation. On the level of appearance, this can be accomplished by managing impressions, but on a deeper level, it requires eliciting emotions from within corresponding to the physical image presented on the outside. The physical proximity and emotional accessibility characteristic of interdependent households means that patients' feelings and moods are subject to as much scrutiny as their physical conditions.

The burden of shaping the terminal illness process to sustain caregivers and keep them from becoming added sources of stress takes its toll on the interdependent types. From a practical point of view, patients such as these could benefit from brief periods of reprieve from the obligations and responsibilities of their households. In much the same way as family members seek respite from their caregiving duties, interdependent types need temporary relief from the emotion work of being terminally ill. Brief stays on palliative units or in nursing homes where staffs are specially trained to minimize their expectations of the patients' emotional labor could provide patients with a needed release from emotional obligations. Therapeutic group sessions in outpatient palliative care settings where patients' feelings can be expressed without fear of upsetting caregivers could also ease the emotional burden of the interdependent types.

Because interdependent types are very sensitive to the feelings of others, pastoral care staff need to develop a degree of self-awareness that allows them to understand the impact of their emotional frames on the patients. Visits from chaplains, for example, have the potential to provide comfort to the interdependent types, but they can also be a source of distress to patients who feel they are expected to respond to pastoral visits by generating appropriate sentiments. Notions of what it means to be a good patient and die a good death weigh heavily on interdependent types, making them especially vulnerable to even the slightest suggestion they have upset others by failing to live up to medical or religious ideals about dying. In the midst of all this, those ministering to interdependent types must also attend to the identity needs of the patients. The loss of self in illness is not peculiar to interdependent types, but their tendency to put others needs before their own makes them susceptible to being overlooked as individuals. Attempts to address the often compelling needs of family members struggling to deal with the loss of a loved one should not overshadow efforts to assist dying patients with issues of self-preservation and self-possession emerging at the end of life.

More than anything else, interdependent types need to feel they are contributing to their own care while looking out for the emotional needs of others. Overly ambitious family members can push patients to the margins of the caregiving process, taking center stage and depriving patients of a sense of belonging. Social workers are ideally situated to intervene in such situations by advising caregivers on ways to include the patients in their own care. Although this does not require complicated procedures or major changes to household routines, it does necessitate the willingness of caregivers to sacrifice some degree of efficiency and forgo time-saving adaptations that, in effect, diminish patient efficacy and transform them into objects of care rather than subjects with inner lives of their own.

Emotions as Process

Although the sociology of emotions has focused on how emotions are generated and managed in varying social situations, interpersonal encounters, and personal crises, sociologists are also interested in how emotions change over time as individuals move through the course of major life events (Hochschild, 1983). In his study of caregiver burden, Karp (2001) discusses the importance of viewing emotions "as emergent properties of a broader stream of social experience" and addresses the need for systematically attending to the processual nature of the emotional life of individuals. As he explains,

> by considering the evolution of caregivers' emotions, I am moving beyond studies that link emotions only to particular incidences, momentary encounters, or discrete events. (p.73) Studies that show how emotions shift in predictable ways through the life course of any important process may also have significant practical value. . . . If we could know in advance the likely sequence of emotions in these and similar social processes, we could better prepare people who will experience them by choice or by chance. (p. 107)

In his analysis of the affective worlds of caregivers, Karp (2001, pp. 73-74) found caregivers' "careers proceed through a predictable series of feeling frames" and that each stage in the caregiver career is guided by a "distinctive cognitive frame that shapes respondents' emotions." For the caregivers in Karp's study, the initial phase of their loved one's mental illness was framed by feelings of bewilderment or "emotional anomie." An official diagnosis of mental illness ushers in the second phase of the caregiving career, during which the medical frame generates a feeling of compassion for the patient. In the third phase of the caregiving career, a "frame of permanence" gives rise to feelings of anger and resentment as loved ones confront their doubts about the patients' capacity to ever manage their own lives. In the final phase of the caregiving career, the "frame of recognition" of powerlessness over the course of the illness leads caregivers to feelings of acceptance (Karp, 2001, pp. 74-75).

If we think about the emotional frames associated with adaptation to cancer as processual rather than as single events in time, we can achieve a better understanding of the lived experience of terminal illness. Among the low-SES patients in this study, individuals categorized as distressers and dismissers have the most recent diagnoses (within 5 to 6 months prior to the start of the study), and their emotional responses to cancer represent two distinct ways that feelings are generated and expressed in the early stages of terminal illness. Similar to Karp's "emotional anomie," the overwhelming feelings of anxiety, fear, and sadness that distressers are unable to contain are what we commonly expect to find among newly-diagnosed cancer patients, especially those who, like the poor, are perceived as overly expressive and emotive in times of crisis.

Of course, we know that not all newly diagnosed cancer patients experience a flood of distressing emotions disrupting their lives and interfering with their capacity to function. Instead, we see a smaller number of individuals who, like dismissers, initially engage terminal illness in a stoic fashion, blocking out their emotions and not allowing themselves to feel the terror of what is tantamount to a death sentence. Interestingly enough, the feeling norms defining the appropriate emotions associated with bad news and tragic events seem to encourage the distresser responses while denying legitimacy to the dismisser responses. Indeed, dismissers are often accused of avoiding reality and are typically labeled as being in denial.

Because terminally ill patients are not expected, or even allowed, to stay in denial or in distress forever, the second phase of feeling norms associated with terminal illness frames the emotions of individuals who have survived the first 6 months of their cancer diagnoses. With a mean time since diagnosis of 16 months, individuals like those in the shaper and relinquisher categories operate out of a set of emotion rules that attempt to generate feelings of faith and confidence in their ability to get well. While shapers try to generate positive emotions and elicit them from others by focusing on possibilities rather than probabilities, relinquishers struggle to assume the upbeat stance their caregivers require. It is the emotion of hope that emerges as the dominant feeling in this period of the terminal illness career and frames patients' lived experiences of terminal illness.

Because they do conform to the feeling frames for the second phase of terminal illness, individuals who do not move beyond the distresser or dismisser modes and continue to exhibit the extremes of excess emotionality or stoicism are perceived as deviant. Among low-SES patients, those most likely to miss the transition from initial distress or stoicism to hope fall on the two extremes of the family affective dynamic. Low-SES White men and women with high degrees of family embeddedness have a tendency to remain distressed throughout the illness trajectory, while Black men with high levels of detachment from family tend to hold on to the dismisser stance even to their death.

Episodes of depression often accompanying a terminal diagnosis may become intractable during the second phase of the illness as patients unsuccessfully deal with others' unrealistic expectations of them. Those patients most likely to be depressed and anxious rather than confident and hopeful are the distressers and relinquishers. For distressers and their families, sadness is a recurring element in the feeling frame of terminal illness. For relinquishers, however, feelings of depression emerge when patients are unable to conform to caregiver expectations and successfully navigate the transition from fear to hope. Although temporary depression is a normative feeling frame for cancer patients, intractable sadness is often perceived among the terminally ill poor as a sign of weakness and a failure of willpower. While it is anticipated that patients will feel depressed by the prospect of physical decline and diminished longevity, it is not expected that they will be overpowered by sadness. For these reasons, when feelings of depression emerge when feelings of hope are to be expected, the terminally ill poor move beyond the boundaries of physical illness and enter the realm of mental illness, where sanctions for moral failings are more stringently enforced.

For patients whose terminal illness experience extends beyond 2 years without any hope of a cure, feelings of optimism often give way to a sense of endurance. With a mean time since diagnosis of 30 months, patients like sustainers and resisters attempt to hang on to life as they know it by not allowing others' feeling frames to alter the status quo and diminish their capacity to function. The affective frames that shape patients' approaches to living with terminal cancer for extended periods of time are similar to the rules for managing chronic illness, because they expect patients to "hold their own" and "bear up" under the weight of long-term stress. The low-SES patients best situated to adopt the feeling frame of endurance are typically single Black women in charge of households and married Black men supporting their wives (sustainers and resisters). With a stance toward adversity that predisposes them to put illness on the back burner and tend to the urgent economic realities of their lives, sustainers and resisters are least likely to allow themselves to feel distressed or to get hooked on the feeling frame of hope. Indeed, the longer they live with cancer, the more likely they are to feel as it they should not let the illness get them down or lull them into thinking they will live forever.

Not all patients who survive the first two years of their illness adopt the feeling frame of endurance. Those longterm survivors who remain in the distresser mode for the duration of their disease trajectory or who continue to depend on others to elicit hopeful emotions usually generate the highest level of caregiver stress among their loved ones. Because of their inability to move out of the feeling frames that are acceptable in the earlier stages of illness, distressers and relinquishers make demands on the emotional lives of family and friends that erode caregiver support. The negative feedback they get from emotionally-burdened loved ones only aggravates the situation by intensifying feelings of depression and anxiety. Dismissers, too, do not fare well if they maintain their characteristic feeling frame throughout the illness trajectory, burning their bridges behind them and alienating caregivers in the process. On the opposite end of the emotional spectrum, however, are the shapers who, in spite of evidence to the contrary, maintain feelings of hope over the long haul. Because of their capacity to translate faith and hope into positive health outcomes for themselves and diminished stress for their caregivers, patients like shapers are of particular interest to researchers in the fields of medicine and social science alike.

Limitations and Strengths of the Study

From a methodological point of view, the findings presented here have limited generalizability because the research was conducted on a convenience sample rather than a random sample of cancer patients. The small size of the sample and the even smaller number of power in some of the categories limits its generalizability as well. Although a total of 33 subjects is sufficient for qualitative research, a larger sample would provide greater support to the viability of the six types of coping strategies that emerged. The absence of a systematic means of differentiating the subjects into coping categories based on objective criteria also makes it difficult to confirm the validity of the six types. While patients have been assigned to categories that conform to their preferences for relating and styles of coping, the sorting process remains essentially a subjective one based on observations of patients' behaviors at the clinic and interpretations of their responses to interview questions. Further research in this area needs to begin with the development of objective criteria for differentiating the coping strategies of low-SES patients. Findings on coping strategies from low-SES settings should be compared to the coping styles of more affluent terminally ill patients. In addition, data on patients suffering from non-life-threatening chronic conditions can be used to determine if the coping strategies identified here are unique to low-income, terminally ill patients. We must not overlook the possibility that terminal illness and not poverty is the operative factor.

The strengths of this study are found in the capacity of qualitative methods to capture the process patients experience when dealing with stressful events in their lives. By permitting patients to talk at length about their adaptations to terminal cancer, the open-ended conversational approach used in this study allows respondents to link disparate events and identify the turning points in their transitions from health to illness. The structure and content of the instrument itself is based on a processual understanding of the life course, enabling patients to articulate the changes that have occurred over time as they move through a series of awareness contexts and feelings frames associated with terminal illness. Most importantly, in-depth interviewing allows patients to talk at length about that is important to them.

Unlike causal models which offer "an abstract quantitative representation of real world dynamics" (Marshall, 1996, p. 43), processual models are grounded and relevant in the lived experience of respondents. While causal modeling begins with an hypothesis about how variables influence one another in some sort of hierarchical fashion, processual approaches start with the assumption that variables are temporally linked through the continuity that connects the flow of events in patients' lives. Rather than conducting research through the lens of causality that is impossible to prove, qualitative researchers frame their investigations from the perspective of change over time as it is documented in the first-hand accounts of patients' lives. Although causal modeling utilizes flow graphs with directional arrows between variables to illustrate a chain of multiple effects, it is an essentially static approach incapable of capturing the dynamic that moves individuals through the trajectory of human life.

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APPENDIX A

INTERVIEW GUIDE

Section 1: Demographic Information

1. What is your age and place of birth? (when and where were you born?)
2. What is your gender (sex)?
3. What is your race?
4. What is your marital status? [Single, married, divorced, separated, common law]
5. What is the highest grade of schooling you completed? If you did not complete high school, please explain why. Did you get your GED?
6. Do you own your own car? Are you able to drive? How did you get to the clinic?
7. In what town or city do you live? How long have you lived in there?
8. Do you live in a house, apartment, trailer or other type of dwelling? How long have you lived in that particular dwelling? Who owns the place where you live?
9. Do you live alone? If not, what is your relationship to those who live with you?
10. Do you have any children? If so, what are their ages and where do they live?
11. Do you have any brothers or sisters? If so, where do they live? How old are they?
12. Is your mother still living? If so, how old is she and where does she live? If not, when did she die, and how old was she when she died? What caused her death?
13. Is your father still living? If so, how old is he and where does he live? If not, when did he die, and how old was he at the time of his death? What caused of his death?
14. Were you raised by anyone other than your biological parents? If so, what was their relationship to you? In addition to parents, guardians, sisters/brothers, spouse, and children, tell me about any other family members (including in-laws and step-relationships) that are important to you in your life.
15. Did you have any family problems before you got sick? Do you have any now?
16. Are you the primary caregiver for anyone in your family? Has your illness affected your ability to care for them?
17. Are their any medical conditions that seem to run in your family? If so, what are they and which family members have been affected?
18. Did you have any financial problems before you got sick? Do you have any now?
19. What kind of work did you do before your illness? How long had you been working in that type of work? Did your job provide any medical benefits? If you were not working before your illness, how did you support yourself and pay medical costs?
20. Are you presently working? If not, how long has it been since you've worked? What is your major source of income at present? Do you receive any financial help in addition to this? Are you receiving any medical benefits now?
21. Can you estimate the total monthly income before taxes for your household before your illness?
    (A)$500.00 or less (B)$501.00 to $750.00 (C)$751.00 to $1000.00
    (D)$1001.00 to $1500.00 (E)$1501.00 to $2000.00 (F)$2001.00 to $2500.00
    (G)$2501.00 to $3000.00 (H) over $3000
22. Can you estimate the total monthly income before taxes for your household for last month?
    (A)$500.00 or less (B)$501.00 to $750.00 (C)$751.00 to $1000.00
    (D)$1001.00 to $1500.00 (E)$1501.00 to $2000.00 (F)$2001.00 to $2500.00
    (G)$2501.00 to $3000.00 (H) over $3000
23. Do you identify with any particular religion? (please specify) Are you an active member of any church? If so, what activities do you like to take part in at church?

Section 2: Information on Pre-Diagnostic, Diagnostic, and Treatment Phases of Cancer

24. What was your life like before the diagnosis? How did you spend your days? What events and activities were important to you?
25. Before you became ill, what achievements meant the most to you? What were you the most proud of?
26. Before you became ill, how did you see your future? What did you think it would be like? Did you have any plans for your retirement years?
27. Before the illness, had you experienced any major losses in your life?
28. How was your health history up to the time of the diagnosis?
29. What were the symptoms that led to the diagnosis?
30. How long did the symptoms last before you sought medical care? If you did not seek help early in the symptoms, why did you put if off? What finally made you go to the doctor?
31. What is your medical diagnosis? When were you diagnosed (how long ago)?
32. How long did you have to wait for your diagnosis?
33. How did you learn of your diagnosis? Who did you learn it from? How do you feel about the way your diagnosis was communicated to you?
34. What was your reaction to the diagnosis? What were your initial thoughts when learning that you had cancer? How did you cope with the diagnosis?
35. Did you share the information about your diagnosis with others? If so, with whom? How did they react?
36. Are there some people that you did not tell your diagnosis? If so, why didn't you tell them?
37. Do you have any idea of what caused the cancer?
38. Describe the course that the cancer has followed (Have you been in remission? Have you had any reoccurrence? Has the cancer spread?) At what point did you come to realize that your illness might be incurable?
39. Please describe the treatments that you have had for the cancer. Have you been hospitalized for the cancer? If so, what was that experience like?
40. Describe your experiences as an outpatient receiving treatments for the cancer. What kind of treatments will you be receiving at the clinic today?
41. How do you cope with the treatments and their side effects? Have the treatments affected you emotionally or physically? Are there any activities that you are no longer able to do?
42. What are your thoughts and feelings now about the diagnosis, treatments, and their outcomes? Would you have made different treatment choices if you knew then what you know now?
43. Has your life changed in any other ways since the diagnosis? Do you spend your time differently now than you did before? Is there anything you miss about your life before the illness and its treatments?
44. Are there things that you worry about now that you did not worry about before? Are there things that you worried about before that no longer worry you?
45. Looking back over your entire illness since you first became aware of your diagnosis, what has been the most difficult period for you? What are your major concerns now? What are the most difficult things about your illness now?

Section 3: Doctor-Patient Communication

46. Have you had the same doctors and nurses throughout your treatment? How would you describe your relationship with your doctors and nurses? Do you feel they provide you with the facts you need and allow you to make your own decisions about your care?
47. Are there any ways that doctors, nurses, and hospitals could improve how they treat cancer patients?
48. Have you gone to any medical providers other than traditional doctors? How did you find out about them? What kind of treatments and medications have you received from them?
49. What is your understanding of what the doctor said about the seriousness of your illness and your chances of survival or a cure? Have you had this understanding since the start of your treatment or is it something that you came to realize gradually?
50. Do you believe what the doctor has told you about your chances for survival? Why?
51. Some doctors do not tell the patient that they have an incurable illness. If you could do it all over again, would you rather not know? Explain.
52. Some terminally ill patients ask their doctors for help in ending their lives. Do you think that it is right for doctors to help patients die? Have you ever considered this for yourself?

Section 4: Normative Elements of the Terminal Illness Experience

53. How should people with cancer act? Are there any kinds of things they should or should not be doing?
54. How should people with cancer be treated by others? Are there things that others should or should not do with them or for them?
55. Describe what it is like for you as a person to have cancer. Do you feel differently about yourself?
56. Do you ever feel that you may be letting someone down or failing to meet someone's expectations of you? In what ways?
57. If you could speak to someone who has just been diagnosed with cancer, what things do you think it would be important for them to know?

Section 5: Coping Strategies and Social and Psychological Resources

58. Do you feel that what happens to you and your illness is under your control? Have you ever felt overwhelmed or helpless by any aspect of your illness or treatment?
59. How are you coping with your illness and all the changes in your life?
60. Do you turn to anyone in particular for emotional support? How do they support you? Do you feel that you are getting the emotional support you need? If not, what is missing?
61. Can you talk honestly and openly with anyone about your feelings and concerns about your life right now?
62. Do you turn to anyone in particular for help with practical everyday needs like transportation or running errands? How often do you ask for their help? Are they able to give you as much help as you need?

63. Who provides your physical care when you are at home? Have you thought about Hospice Care? Is there a family member or friend who could be your caregiver?
64. Have you experienced a sense of loss or sadness from your experience with cancer? If so, how would your describe this sense of sadness or loss?
65. Have you looked for comfort in religion or prayer? If so, please describe how you seek it?
66. Are you receiving spiritual help from anyone? If so, from whom? How does this spiritual help affect the way you think and feel about your illness?
67. Has your illness had any effect on your self-esteem? If so, in what ways?
68. Are you receiving psychological counseling from anyone? If so, from whom? Does this psychological help affect the way you think and feel about your illness?
69. Has anyone offered you information about cancer support groups? If yes, have you attended any meetings? Why/why not? If you have not received any information about support groups, would you be interested in visiting a support group meeting? Why/why not?
70. Who has been the greatest comfort to you during this entire experience? What has been the greatest comfort to you during this entire experience?
71. Have relationships with family and friends changed during your illness? If so, how?
72. Before your illness, who were the most important persons in your life? What relationships gave your life meaning? Who are the most important people now? What relationships are giving your life meaning now?
73. Do you see anything positive about your current situation?

Section 6: Final Thoughts

74. What are your greatest hopes at this time? What are your greatest fears?
75. When you think about the future now, what kinds of things come to mind? Are there special events in the future that you would like to be alive for?
76. How do you want to be remembered by family and friends after you die?
77. If you could write your own memorial, what would you say about yourself?
78. Have you thought of any possessions you would like to leave to family and friends?
79. All in all, would you say that you have had a fulfilling life? What have been the most fulfilling aspects of your life? Is there anything you want to do before you die?
80. If you could live your life over, would you do anything differently? Do you have any regrets? If so, could you tell me about them?
81. When you think about your death, what comes to mind?
82. Do you believe in an afterlife? If so, how do you envision that afterlife?
83. Finally, is there anything that you think is important to talk about that we've omitted or neglected to ask?

APPENDIX B

INSTITUTIONAL REVIEW BOARD APPROVAL FORM

UAB THE UNIVERSITY OF
ALABAMA AT BIRMINGHAM

Institutional Review Board for Human Use

Form 4: IRB Approval Form
Identification and Certification of Research
Projects Involving Human Subjects

The Institutional Review Board for Human Use (IRB) has an approved Multiple Project Assurance with the Department of Health and Human Services and is in compliance with 21 CFR Parts 50 and 56 and ICH GCP Guidelines. The Assurance became effective on January 1, 1999 and the approval period is for five years. The Assurance number is M-1149.

Principal Investigator: WILLIAMS, BEVERLY ROSA

Co-Investigator(s):

Protocol Number: **X990812003**

Protocol Title: *A Study of Coping with Cancer*

The IRB reviewed and approved the above named project on 04/02/02. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.

IRB Approval Date: 4-2-02

Date IRB Approval Issued: 04/04/02

Marilyn Doss

Marilyn Doss, M.A.
Vice Chair of the Institutional Review
Board for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.

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GRADUATE SCHOOL
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DISSERTATION APPROVAL FORM
DOCTOR OF PHILOSOPHY

Name of Candidate Beverly Rosa Williams

Graduate Program Medical Sociology

Title of Dissertation Coping With Cancer: Strategies for Dealing With Terminal Illness

I certify that I have read this document and examined the student regarding its content. In my opinion, this dissertation conforms to acceptable standards of scholarly presentation and is adequate in scope and quality, and the attainments of this student are such that she may be recommended for the degree of Doctor of Philosophy.

Dissertation Committee:

Name	**Signature**
William C. Yoels, **Chair**	William C. Yoels
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Patricia Baker	Patricia S. Baker
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Date 5/16/02