# CANCER SUPPORT GROUPS AS SUBCULTURAL PHENONMENAL

By

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To Max, Quinn, and Alexander
for sacrifices made

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# CHAPTER I

# INTRODUCTION

> Some people didn't want to hear about it.  And some people did but for the wrong reasons.  And some, like my father, wanted to but weren't easily able.  They were afraid.  After a few uneasy receptions, I began to temper myself, to choose the moment and the ear more carefully, and in the process, I learned about dignity.
>
> Katherine Russell Rich in *The Red Devil*

> Regrettably, there appears to be a paradox for the cancer patient, in that, whilst social support is a potentially strong resource for adjustment, the disease of cancer interferes with its provision.
>
> Winefield and Neuling in *British Journal of Guidance and Counselling*

In her autobiography, Rich succinctly summarizes the "disconnect" felt by many persons with cancer: cancer can and does alienate individuals from significant others and everyday experiences by thrusting them into the unfamiliar territory of a managing a life-threatening illness.  Cancer encompasses a collection of over 100 illnesses characterized by the uncontrolled growth and spread of abnormal cells.  Left uncontrolled, the spread of abnormal cells generally results in death. The cancer literature is replete with accounts of the loss of control and predictability over one's environment as a consequence of being diagnosed with cancer.  The term "cancer" continues to be synonymous with a painful and untimely demise, even though a cancer diagnosis no longer confers an automatic death sentence.  Other illnesses with more dismal outcomes evoke far less terror than cancer does (Weisman and Worden, 1976).

The existential plight of the cancer patient as described by Weisman and Worden "signifies an exacerbation of thought about life and death" brought about by cancer (p. 3, 1976). Cancer patients can become quickly consumed emotionally by an illness over which they have little influence and, for some, little understanding.  Patients must begin to make a multitude of weighty decisions about their disease regarding physician choice, treatment strategies, and care setting that all influence the likelihood of surviving (Dunkel-Schetter and Wortman, 1982). Most people have never been placed in the situation of having to sift through enormous amounts of information that can be voluminous, conflicting, and highly technical. The confusion generated by the cancer experience coupled with diminished control may create feelings of vulnerability and personal inadequacy (Helgeson and Cohen, 1996).

In grappling with sizable difficulties and decisions imposed by a potentially life threatening disease, empathy from others may be hard to find. The stigma accompanying cancer may negatively influence the relationships with family, friends, and employers by reminding them of their own mortality. Irrational or erroneous assumptions about pain, suffering, and/or death associated with cancer may lead the healthy to avoid, respond inappropriately to, or gloss over the problems facing cancer patients. Evidence suggests that in the presence of cancer, sources of support evaporate, leaving cancer patients to contend with feelings of guilt, isolation, and stigmatization on their own (Bloom and Kessler, 1994). Thus, the misconceptions about cancer create fear and ambiguity that only serve to perpetuate the stigma surrounding cancer.

Cancer patients, in particular, experience intense social support needs that may persist over a dramatically extended period of time, as cancer patients are living longer with the disease (Wortman and Dunkle-Schetter, 1979). A cancer diagnosis is often accompanied by a variety of new and different problems including dependence, disability, uncertainty, and changes in self-concept that induce considerable distress (Wortman and Conway, 1985). Social support needs become greater than usual because of the cancer patient's heightened feelings of vulnerability both physically and emotionally. For example, patients may find themselves frightened by the unpredictability of their cancer or worrying that their reactions are not normal. As a result, they experience the need to clarify their situation and their feelings through discussion with and feedback from others. Those others may include health care providers such as doctors or nurses, family and friends; however, the evidence increasingly shows that not all social support is equal and that the best social support may come from similar others (Taylor et al., 1986).

In order to cope with acute feelings of emotional distress and to acquire empathetic understanding, people with cancer may seek coping assistance from cancer support groups. Support group members may offer a more thorough and nuanced understanding of the situation shared by the distressed cancer patient based on their perspectives and comprehension, otherwise unavailable in the larger population (Francis, 1997). Fellow cancer patients may be in the best position to dispel fears and misconceptions associated with the stigma of cancer and offer helpful advice and clarification. In this way, similar others may be able to offer the best social support (Thoits, 1986).

In order to show how this process might unfold, I will demonstrate the roles that "emotional deviance" (persistent feelings of distress that alienate patients from the mainstream) and cancer as a stigmatizing condition play among cancer patients who contend with persistent feelings of distress that alienate them from the mainstream, prompting them to seek similar others who can help transform such feelings. The uncertainty accompanying cancer and anxiety surrounding diagnosis and treatment contribute to the often emotionally debilitating nature of the illness and accompanying stigma. Cancer support groups offer empathetic understanding by providing legitimacy for emotions and problems that fall outside the mainstream experience. Consequently, like other subcultures, cancer support groups create and refine their own responses to cope with the stress induced by being socially differentiated. In this sense, support groups, like subcultures, serve as an avenue through which coping assistance may be transmitted among a group of similarly typed individuals. In this dissertation, I will argue cancer support group processes may be re-conceptualized as a subcultural phenomenon that emerges within a specifically distressed population, in this instance, persons with cancer.

## Review of the Literature

### The Origins of Subculture

Writing as early as 1960, Milton Yinger noted that the term subculture had been used "as an ad hoc concept whenever a writer wished to emphasize the normative aspects of behavior that differed from some general standard" (p. 626). The broad spectrum of research that claims to represent subcultural phenomena seems to underscore Yinger's observation: for example, BASE jumpers (Ferrell and Milovanovic, 2001), Jewish bikers (Martel, 2001), Brazilian transvestites (Inciardi et al., 1999) and intravenous drug users (des Jarlais and Friedman, 1987). Taken together these studies often apply the term subculture in different ways and ignore the need to be precise or consistent in usage. Fine and Kleinman (1979) contend that much of the research literature treats subculture as a “reified system which refers to a discrete, easily definable population segment, ignoring the difficulties involved in defining the concept” (p. 2). They add that any discussion of subcultures implies some contrast to a referent population, the evidence for which needs to be made explicit to understand the boundaries of both.

Possibly the most commonly applied interpretations of subculture are those provided by Albert Cohen and Milton Yinger (for a full review see Fine and Kleinman, 1979). In his discussion of delinquent gangs, Cohen describes subculture as “a design for living which is different from or indifferent to or even in conflict with the norms of the ‘respectable’ adult society” (p. 24, 1955). His interpretation of subculture as the subordinant group’s frustration with the dominant group’s traditional norms and values serves as the classic conceptualization of delinquency used by sociological criminologists (Hagan, 1991). Yinger, on the other hand, defines subculture as a set of norms that arises from the successful socialization into a smaller sub-society that sets it apart from total society (1960). In other words, a subculture may be distinguished from the dominant culture by its own distinct normative system.

Using the norms and values of mainstream society as a referent, these definitions of subculture taken together provide only a partially complete description of subculture. To make a convincing argument that a subculture exists, Fine and Kleinman argue that one must also delineate stable yet distinctive features of the group, demonstrate that members identify with the group, and illustrate the transmission of group culture among members (1979). Thus, a subculture may be broadly defined as a collective group of persons whose patterns of behavior reflect an alternate, but distinct set of norms, values, and beliefs from those of mainstream culture. Members must identify with the subculture, and exchange information and values characteristic of the subculture.

Although the notion of a subculture is most notably applied to criminal and delinquent acts, it has also served as a useful theoretical tool to apply to other kinds of frustrated responses to mainstream culture (e.g., Appalachian peoples’ persistent cycle of poverty). Subcultural theories posit that individuals who define themselves similarly, but outside the bounds of mainstream culture, will band together and organize around a shared commitment values and beliefs (Irwin, 1970). In order to understand how the scope of subcultural phenomena may encompass cancer support groups, I will illustrate how sociological criminology laid the groundwork for subcultural research as a whole.

The discussion of subcultures first began in the 1950s as researchers attempted to explain high rates of crime among lower class juvenile delinquents engaged in gang activity. Within criminological theory, two branches of major causal theories attempted to address subcultures' origins and continuity: structural strain and cultural conflict[1]. Subcultures could arise on the macro level through limitations produced by structural conditions (e.g., discrimination, inequality) (Valentine, 1968) or on the micro level through opportunities provided by one's local culture (e.g., gangs) (Cloward and Ohlin, 1960).

In the structural strain tradition, Merton (1938) explains delinquency as arising from the gap between Americans' overemphasis on monetary success and the comparatively de-emphasized means for achieving such success. As a result, individuals who cannot achieve success due to the inaccessibility of conventional means will experience strain and frustration and will resort to illegitimate avenues in order to reach their goals. He views lower class and minority Americans, in particular, as sharing socially approved goals of success while, at the same time, feeling less committed to following legal norms to gain such success (Akers, 1997). To overcome the status problems induced by the strain between conventional opportunities and structural limitations, lower class youth to resort to criminal means for achieving success. Involvement in criminal means of success represents a contrasting set of alternative values to the values of mainstream culture, characteristic of subcultures.

Focusing upon lower class delinquent youth specifically, Cohen (1955) views criminal behavior as the result of the frustration of lower class boys *insufficiently socialized* to achieve middle class status requirements. Cohen shifts his focus from achieving a certain level of material success as conceptualized by Merton to acquiring a certain level of status within conventional society (Thio, 1998). In a collective effort to resolve their status frustration, delinquent boys create their own set of standards in opposition to dominant values that Cohen calls the "delinquent subculture" (p.24, 1955). According to Cohen, the "non-utilitarian,

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[1] Cultural conflict is also known as normative conflict.

malicious, and negativistic" characteristics of the delinquent subculture further underscore its "'negative polarity'" to conventional norms (p. 25, 1955).

Finally, Cloward and Ohlin (1960) introduced the concept of differential illegitimate opportunity structure as their way of explaining how some lower class youth may find success within deviant subcultures while others do not. They argue that not all lower class individuals share the same opportunity to participate in deviant activities as assumed by Merton. Illegitimate opportunities present themselves within deviant subcultures where one learns how to perform certain specific criminal acts depending on the illegitimate opportunity structure available in a particular lower class community or neighborhood (Akers, 1997).

Yinger (1960) challenged the structural strain depiction of the delinquent subculture as a simple construct used to indicate a variation from some standard or referent. Instead, he coined an additional term, contraculture, to describe subcultures in direct conflict with the dominant society. Contraculture differs from subculture in that it is fueled by a sense of frustration that can only be understood by its opposition to the surrounding dominant culture. The values and norms associated with a contraculture directly contradict the values and norms of the mainstream. Contracultures push away from society to create social movements such as anti-government groups with the express purpose of countering society's values and practices.

The re-definition of subculture as contraculture resonates with another dominant stream of criminological thought: cultural conflict theory. Cultural conflict theory approaches subcultures as deviant relative to another group's perspective (Miller, 1958). Standards of right and wrong vary by particular segments in society with only powerful groups' standards reflected in the law (Sutherland and Cressey, 1974). Normative behavior interpreted as appropriate for a particular group or category actually may conflict with the law and result in legal sanctions.

Consistent with this perspective, Miller (1958) challenged the structural strain depiction of delinquent subcultures as challenging middle class norms. Instead, Miller argued that the lower class culture to which delinquents belong has a "distinctive tradition" with "an integrity all its own" (p.xx, 1958). The motivation for committing delinquent acts among lower class boys does not come from the need to violate middle class norms, but rather to achieve what is valued within their subcultural tradition (Miller 1958). Delinquent behavior provides the means through which delinquent boys conform to and pursue the values, norms and beliefs of a distinct subgroup of society (Jensen and Rojek, 1998).

Therefore, cultural conflict arises when a person experiences differential exposure to multiple subcultures within a certain society at the individual level (Sutherland and Cressey, 1974). When a person follows the norms of his or her own culture she becomes deviant according to the overarching societal norms represented in the larger culture. Where the structural strain perspective views deviance as an objective product of social or political tension, the cultural conflict perspective approaches deviance as a relative product of competing definitions of right and wrong.

In sum, both the structural strain and cultural conflict traditions in criminology contain several key components to understanding subcultures, which may be shared by support groups. Research in the structural strain tradition suggests that alternative values and norms arise when mainstream goals and values cannot be met. Particular structural opportunities allow for the exposure to and transmission of cultural knowledge essential to creating and sustaining a distinct subculture. Cultural conflict theory explains that subcultural variations exist only relative to the competing beliefs held by the dominant culture. In contrast to contraculture, subcultures arise when individuals who feel rejected come together to develop solutions to mutually experienced problems *within* rather than *apart* from the dominant culture.[2]

Fine and Kleinman's elaboration moves beyond classical subcultural theory by adding an interactionist perspective that explains how identification with the group and the transmission of group culture continually reinforce and replicate the subculture. The authors argue that only through face-to-face interaction can subcultural knowledge be created and diffused. "Subcultural identification is possible only if the individual has the opportunity to interact with others who identify with the population segment and gain cultural information from them" (p. 14, 1979). In identifying with the subculture Fine and Kleinman suggest that members will be motivated "to adopt the artifacts, behaviors, norms, values characteristic of the group" (p. 1, 1979). Congruence over similar values and beliefs regarding their mutual problem or condition

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[2] I do not want to imply that support groups members are seeking to escape from society at large. The boundaries between support groups and mainstream culture are often fluid, providing the coping assistance that allows members to function in their present roles.

promotes a shared common identification (Fine and Kleinman, 1979). Thus, for Fine and Kleinman, continual interaction is the key to the on going production and refinement of values and beliefs that lead to identification with the subculture and continual transmission of its culture.

Through my observational data on cancer support groups, I hope to verify the existence of a subculture through the specific set of norms, beliefs, and shared meanings created and sustained by the social interaction between support group participants. What may appear as irrational or ridiculous to an outsider may be entirely predictable and reasonable within the support group. For example, where prior to the group a cancer patient may see chemotherapy agents as acting as poison making him feel terribly ill, support groups members assist new members in understanding that chemotherapy works as much needed medicine combating deadly cells. Major side effects like hair loss should be interpreted as a sign that chemotherapy is healing one's body rather than as a sign that one is seriously ill[3]. Likewise, where a distressed cancer patient might interpret his or her diagnosis as a sign of being punished by God, fellow support group members may suggest that cancer serves as a positive test of faith to make one stronger.

Drawing upon my observations of cancer patients in support groups, I will also provide evidence for the mutually experienced problems that set them outside the mainstream. Cancer patients may be prompted to join support groups either from the actual avoidance or rejection by others threatened by the stigma of cancer, or by cancer patients' own perceptions of their feelings as inappropriate or non-normative. For example, cancer patients report that sources of social support recede just at the time they are most needed (Wortman and Dunkel-Schetter, 1979). Interpersonal relationships may suffer from a lack of open communication about the patient's condition or from aversion to the situation altogether. The intense fear and uncertainty that accompanies a cancer diagnosis leaves patients with an especially heightened need for support and explanation (Wortman and Dunkel-Schetter, 1979).

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[3] Chemotherapy works by attacking fast growing cells like cancer. Hair growth happens to be some of the "good" fast growing cells that also get wiped out (at least temporarily) in the process, resulting in complete bodily hair loss while being treated. Hair loss is a major source of distress for women in particular.

I suggest that cancer support groups function as subcultures given the evidence for alternatives values, beliefs and norms that depart from or conflict with the mainstream. Support groups may be defined as purposeful creation of face-to-face gatherings of similarly afflicted others that facilitate the mutual exchange of social support. I argue that support groups largely function to provide the cultural knowledge that validates one's deviant feelings and to exchange information and advice that reduces perceptions of stigmatization and emotional deviance. To this end, cancer support groups represent a kind of subcultural phenomenon. In order to understand the how support groups may be analogous to subcultures, I will discuss the forms and functions they serve.

### Support Groups

Support groups encompass nearly all major diseases, life events, transitions, and chronic conditions from birth to death (Remine, Rice, and Ross, 1984). They augment or, in some cases, replace one's social support contacts in everyday life (Gottlieb, 1985). Although firm numbers are difficult to derive, most researchers conclude that anywhere from 500,000 to 750,000 self-help groups exist in the US alone with projections for the 1990s reaching over one million (Katz, 1993). Numerous typologies for support groups abound, particularly as the number of support groups continues to diversify and multiply in the US (Caplan and Killiea, 1976; Katz and Bender, 1990; Borkman, 1999).

Caplan suggests that an individual's support system may be characterized by continuous interactions to provide feedback and validation that compensate for deficiencies in one's larger community (1976). Katz and Bender suggest that support groups arose purposefully to fill the gap for social support unmet by existing social institutions (1976). Support groups appear to have arisen for the same basic reasons as subcultures. The strain between socially approved expectations for behavior and the means of achieving such expectations cannot be met conventionally, sending individuals to search for alternatives. Through the exchange of feelings and information, support groups combat feelings of isolation and social stigma much like the key features of subcultures. In a sense, support groups represent a specialized type of social support intentionally sought by individuals in need of emotional, instrumental, or tangible aid unavailable in their existing social network. Inherent in the social support group setting is the knowledge that one will be immersed in a group of similarly situated others who, by virtue of personal experience, can offer appropriate social support.

Features common to all support groups as identified by Katz (1993) and Wuthnow (1994) include regularly scheduled meeting times, multiple participants, and provision of informational and material aid, with widely varying norms for each. Nonetheless, no single typology captures the entire breadth and range of support groups available given their dramatic growth over the past three decades.[4] Katz separates support groups by what he claims as the most fundamental distinction: twelve step and non-twelve step groups (1993). Twelve step groups are based on the beliefs that individuals must embrace a set path of life-long personal growth and change with a heavily spiritual dimension; conversely, non-twelve step groups tend to be less dogmatic about how growth will take place and do not require a lifetime commitment for change to occur (Katz, 1993). For purposes of this discussion, I will focus only on non-twelve step groups because they characterize the form cancer support groups take.

Typically, support groups have been identified as being either emotion-focused or information-focused in ideological orientation, and either lay or professionally led. Groups that emphasize emotional support tend to be smaller in size while groups that emphasize informational support tend to be larger. Either a professional counselor or layperson with personal experience may facilitate both kinds of groups.

Katz (1981) notes the distinction between the structure of a formalized, professionally led support group versus the structure of an informal, lay-led group. The professional and the '"experientialist"' ("person living with the problem first hand") perspectives each impact the knowledge and ideology generated through support groups (Borkman, 1999). In professionally run groups, the professional dictates the meeting time, format, content and so forth. Professionals' training shapes "their views of a situation, and…provides a suggested strategy to resolve the problem" as defined by the professional, not the participant (p.21, Borkman, 1999). Where a professional can compartmentalize his or her involvement in the problem (as part of his or her occupational role), an experientialist cannot. Because the experientialist suffers from the

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[4] No single type of support group exists even within specific cancer types (Yoak and Chesler, 1985).

focal problem, he or she cannot be as emotionally disengaged as a professional may be because he or she has an immediate stake in the problem. Self-help or lay-led groups emphasize the member, not a professional, as expert. Levy indicates that lay-led groups are more "pragmatically oriented and relatively free of the theoretical dogma to which most professionals are bound (p.311, 1981).

An individual's understanding of his or her situation comes through the ideology promoted by the group that provides a set of explanations (called "specialized system of teachings" by Antze, 1979) for what is happening to him or her. Ideology works to reduce the pain of stigma by generating group cohesion and solidarity through the exchange of shared experiences among similar others and the creation of a standardized outlook (p. 305, Sherman, 1979). The ideology around which the group is organized "will limit the rules of behavior [the leaders] will suggest to [group members] as well as the coping strategies they recommend (Francis, 1997)." Thus, different kinds of support groups are likely to have different styles of offering social support and coping assistance to its members (see Table one). For example in information-focused support groups, one may find reassurance and renewed optimism about one's fate in learning about new scientific advances or understanding causes of treatment side effects (Katz, 1993). On the other hand, emotion-focused groups may accomplish the same goal, but emphasize the experience of fellow group members in role modeling success in adapting to cancer.

Further, Antze describes the central activities that support groups offer as "mutual support and removal of stigma", further adding that ideology provides the persuasiveness essential to attracting and retaining members (1993). The mutual identification with a problem or condition already increases the likelihood that participants will be drawn to the group. However, Antze adds that by the time members arrive at a support group, their high levels of distress may make them particularly receptive to explanations of their situation that provide some relief or clarification. In sharing the group's teachings and personal experiences with new members, ideology may work reflexively to reinforce the beliefs among existing members as well as new ones (Antze, 1993). In this way, the group's ideology draws members into its fold and also binds them to the group.

The interactionist perspective that Fine and Kleinman add to their conception of subculture contains this same ideological element of persuasiveness described by Antze. Support group participants work together to create their own definitions of a stressful situation and solutions to that situation (Francis, 1997). The social interaction among support group members emphasizes particular coping assistance strategies more in line with the support group's understanding of the situation or ideology (Francis, 1997). These strategies might be thought of as part of the cultural knowledge of the group with which people identify that is communicated through face-to-face interaction. In sum, support groups, like subcultures, provide a forum for learning and sharing though personal experience, empathetic support, and information exchange that facilitates members' identification with the group and justifies the group's existence.

Likewise coping norms will be circumscribed by the ideological framework employed by a particular cancer support group. In general, support groups appear to relieve the stress associated with cancer and provide a haven for those who are not treated as "normal" in the ordinary world. For example, individuals who attend "wellness" (emotion-focused) groups at Gilda's Club, a nation-wide cancer support organization, are expected to attend each weekly meeting unless they withdraw from the group or call ahead to say they will not be attending that meeting. Group members are expected to call and provide a reason for not showing. The insistence on group attendance serves as an example of a coping norm that promotes the retention of members. Other groups may allow members to enter and exit as the members' needs for the group change over time. An individual seeking to limit his or her emotional involvement and procure information may choose a larger, more formal group. In this instance, coping norms serve to promote and perpetuate the very existence of the particular support group and its ideology, thereby shaping group interaction accordingly (Francis, 1997).

Together group structure and ideology will influence the means through which members enlist the help of others in trying to cope with their cancer experience. In turn the means and kinds of social support provided by fellow group members will be similarly affected. "Basic differences in ideological commitments are closely related to structure and dynamics of various groups' development, to the kinds of participation they evoke, and the benefits that members seem to obtain from them" (p.68, Katz, 1993). Both ideology and structure influence the social support process thereby affecting the potential range of social support and coping assistance one might hope to receive in that particular format. Ideology may be reflected in norms and values of the support group that shape the ways in which group members cope with their cancer as well as shape the types of social support offered in return.

In describing the key features and processes of support groups, I argue that these same features characterize subcultures, too. Support groups and subcultures arise in response the unmet needs of similarly afflicted persons. Both have ideologies and norms to assist participants in counteracting the negative attitudes of and poor treatment by others from mainstream culture and to promote their adherence to the group. Through repeated interaction with fellow participants, ideology and norms are enacted again and again in ways that sustain the support group's existence.

### Stigma

Although cancer support groups share several key features in common with subcultures, how and why cancer patients join support groups may appear to differ from how and why persons join subcultures. However, drawing from Goffman's observations of stigma and from emotions theory, I will argue that both stigma and "emotional deviance" set people apart from mainstream culture and that support groups are a response to the frustration with the responses of members of the mainstream to their illness.

According to Goffman, a personal attribute becomes a stigma "when it extensively discredits an individual" (p. 3, 1963). Conversely, those who lack a discrediting attribute and thus do not depart from particular expectations may be called "normals". Whether an attribute is considered a stigma or simply an ordinary characteristic depends on the larger social context in which it is placed. The "discredited" are often readily discernable in the form of a visible physical deformity, character flaw, or tribal attribute (e.g., skin color, language or religious symbols). The "discreditable", on the other hand, possess a stigma not readily discernable or immediately apparent. Where the discredited must manage the tension between themselves and the normals, the discreditable must manage the undisclosed information about themselves to avoid being exposed.

Goffman focuses his attention on the point of contact between the stigmatized and the normal in which normals can choose either to ignore the stigma, to treat the stigmatized as a non-person, or to address the stigma directly.[5] Normals may perceive the stigmatized as not quite human, develop an explanation for the inferiority of the stigmatized, and impute further imperfections on the basis of the stigma. The stigmatized person holds the belief that s/he is a normal person, but perceives that others do not accept her/him as equal (Goffman, 1963). When the stigmatized and normals do encounter each other, the stigmatized may feel unsure about their reception by others and whether they'll be categorized favorably or unfavorably. They may feel self-conscious by being either overly praised for ordinary accomplishments or unduly faulted for minor improprieties. In any event, the stigmatized feel a sense of obligation to put normals at ease and reduce tension in order to prove a "good adjustment" to their condition.

The discreditable, unlike the discredited, may try to pass for normal depending on the visibility of the stigma. Repeated contact with others may provide small clues that when taken together can reveal damaging information. Consequently, the discreditable must "stay close to the place where he can refurbish his disguise" (p.x, Goffman, 1963) and guard against any unanticipated social situations in which he might be exposed. Keeping the stigma concealed may involve eliminating any outward signs of stigma (e.g., name changing), using a cover for one's identity (e.g., heterosexual marriage), or attributing one's stigma as a less discrediting attribute (e.g., day dreamer). In other words, the discredited must learn to "reconstitute their conduct" in order to disguise the stigmatizing information about themselves.

Sympathetic others may be characterized by two groups of people: those who share the stigma and can provide empathetic support; and those normals who understand the stigmatized and achieve acceptance among the stigmatized group, often because of family or friendship ties to the stigmatized. Through socialization the stigmatized learn to incorporate the viewpoint of normals and how normals see their stigma and its consequences. The stigmatized may form "huddle together self-help clubs" (e.g., Alcoholics Anonymous) comprised of "sympathetic

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[5] Goffman argues that stigma management pertains to public life since intimates usually have a more realistic assessment of the stigmatized's personal qualities.

others" who share a stigmatizing condition or trait (p.20, Goffman, 1963). Fellow members offer "instruction in the tricks of the trade", provide "a circle of lament" for support, and ultimately acceptance "like any other normal person" (p.20, Goffman, 1963). Thus, "the relationship of the stigmatized individual to the informal community and organizations of his own kind is crucial" in providing support (p.38, Goffman, 1963).

The key to the creation of stigma comes from the symbolic interactionist tenet that an individual's identity is a reflection of others' perceptions. Goffman underscores the importance of the social interaction between the stigmatized and the normals, and the power normals have for defining the world of the stigmatized. This point of contact has important relevance in understanding emotional deviance. Goffman asserts that the stigmatized perceive themselves from the "normal" perspective and assess their appearance, feelings, and actions accordingly. Whether due to one's condition and/or people's negative perceptions or behaviors toward one's condition, the stigmatized may come to understand their own appearance, feelings, and reactions as departing from the norm. In other words, they share in the societal devaluation of themselves by taking the role of the other.

The stigma attached to cancer has been described as tantamount to that of lepers in previous centuries (McCloy and Lansner, 1981). The literature on the interpersonal dynamics between cancer patients and their social networks documents repeated instances of discrimination, mistreatment, misunderstanding and avoidance by others (Wortman and Dunkel-Schetter, 1979; Wortman, 1984). At the root of the cancer stigma seem to be fear and helplessness. Previous research by Bloom found that the predominant "misconceptions about cancer are the overestimation of mortality and the underestimation of the ability to control cancer" (p.120, Bloom and Kessler, 1994). They argue that for the healthy, being the presence of a cancer patient is akin to being in the presence of death.

The negative feelings held towards persons facing life crises may be understood in relation to the notion of a "just world" (Wortman and Lehman, 1985). A belief in a just world motivates people to search for causation for why an individual may be the victim of unfortunate life circumstances. This search is an effort to reduce feelings of helplessness and feel protected from the same fate (Wortman and Lehman, 1985). In looking to explain how someone might have brought cancer upon himself, one might pinpoint a personal failing such as past smoking behavior or unfortunate circumstance such as asbestos exposure. The inability to attribute a cancer diagnosis to a cause serves only to heighten the threat of cancer because conceivably anyone could be next (Bloom and Kessler, 1994; Wortman and Lehman, 1985). These feelings of being threatened, being helpless and lacking control lead others to avoid the person with cancer and deny him or her support. The psychological and physical withdrawal of others may be interpreted by the cancer patient as " a metaphorical statement of feeling already dead" (p. 836, Bloom and Spiegel, 1984).

One of the earliest studies on the psychological aspects of cancer documented the emotional vulnerability experienced by persons diagnosed with cancer (Weisman and Worden, 1976). Estimates of psychological morbidity, including depression, anxiety, and diminished self-esteem, among various cancer patient populations range between 23% and 66% (Somerfield and Curbow, 1992). However, cancer patients have demonstrated great variability in adjustment to their condition and not all necessarily experience emotional distress (Somerfield and Curbow, 1992). Social support has been shown to be a crucial factor in reducing the risk for developing psychological morbidity, with emotional support from family and friends reported to be the most helpful (Dakof and Taylor, 1990; Bloom and Spiegel, 1984; Spenser, Carver, and Price, 1998). Conversely, among the most unhelpful behaviors reported by cancer patients is the withdrawal of significant others (Dakof and Taylor, 1990).

Feelings of distress and an inability to manage those feelings may lead to self-attributions of emotional deviance and draw further negative attention to themselves from others (Thoits, 1985). Wortman and Dunkel-Schetter suggest that the consistency of negative or ambiguous messages from others may eventually become incorporated into the patient's view of himself, leading him to feel shameful and guilty (1982). Goffman describes the retreat into a subculture as one way of solving the interactional difficulties and psychological traumas caused by stigma. Surrounded by others like oneself, one no longer faces devaluation and rejection, alleviating the distress caused by interactions with normals.

### Emotional Deviance

Hochschild (1979) first suggested the existence of “feeling rules” that govern interpersonal interactions in a given situation. Feeling norms implicitly delineate a range of suitable feelings for specific situations, learned through social exchanges. Situations also implicitly carry guidelines for the duration and intensity “of what it is fitting to feel” (p. 563); consequently, the realization that one may be out of step with social convention serves as reminder that that person has violated a feeling norm (Hochschild, 1979). Expression norms guide how one should outwardly display one’s feelings in a certain situation. People can manage deviant feelings in certain situations either behaviorally or emotionally to transform them into a more normative reaction (Thoits, 1990). Emotion management represents a person’s attempt to align what she *should* feel or express with what she *actually* does feel or express (Hochschild, 1979).

Emotional deviance arises when one’s emotional reaction or display fails to fall within the range of appropriate emotions, appropriate duration, or targets for a particular situation (Thoits 1985). Following Thoits’ elaboration of self-labeling processes, a person first defines herself as deviant when her emotional reaction does not match the governing emotion norm for that situation (1985). Awareness of emotional deviance may arise either through imagined self-labeling through the eyes of others or through acceptance of others’ labeling (Thoits, 1985). Central to the understanding of the self-labeling processes suggested by Thoits is the ability of persons to take the role of the other *vicariously* (1985). One does not require the actual actions of others to know how they may respond to or think about one’s intended or actual actions. Self-labeling assumes that individuals are well socialized enough to know the normative expectations for appropriate behavior and emotions in certain situations and to recognize violations (Thoits, 1985).

In the course of social interaction, others without cancer may be uncertain about how or when to help (Goffman, 1963). Cancer patients may only serve to remind them of their own mortality and vulnerability, resulting in avoidance. The ability to take the role of the other permits individuals to see themselves from the perspective of others, thereby anticipating others’ reactions to them. As the distress of a cancer patient increases, the more threatened others may become by the patient’s plight (Dunkel-Schetter and Wortman, 1982). Thus the inappropriate or insufficient reactions of others may only compound a cancer patient’s already existing negative feelings of worthlessness. Emotional distress that is perceived as unrelenting and uncontrollable may lead to perceptions of oneself as abnormal or deviant (Thoits, 1985).

Unrelenting feelings of emotional distress may prompt voluntary help-seeking behavior (Thoits, 1985). Thoits hypothesizes that joining a support group is an attempt to manage the persistent negative feelings stemming from distress – in this case the distress associated with the diagnosis, management and treatment of cancer. Cancer patients indicate that time at first diagnosis, chemotherapy, metastasis, and potential death all represent particularly stressful periods that accompany the illness (Dunkel-Schetter, 1984). When in the company of similar others, that same distress may be reduced through receiving empathetic understanding. To rephrase, support groups provide an opportunity for similarly situated individuals to offer social support and gain coping assistance in dealing with their fear and uncertainty about their predicament (stemming from their distress) (Thoits, 1986). What may appear as irrational or ridiculous to an outsider may be entirely predictable and reasonable to a similarly situated other. Social support may serve as the means through which self-concepts are protected as well as problem-solving skills acquired. Support groups transmit clear behaviors, norms, values, and knowledge for members to follow (such as never talking about death, always being positive despite the odds, always be a survivor and never a victim).

The social interaction among support group members emphasizes particular social support strategies in the form of coping assistance generated by the support group’s understanding of the situation (Francis, 1997). Coping assistance refers to the actions of others in managing an individual’s stressful situation (Thoits, 1986). In this way, similar others may actively participate in reducing the stress and anxiety related to cancer by assisting to change the meaning of the situation, to change the emotional reaction to the situation, or to change the situation itself (Thoits, 1986). For example, a cancer patient may see chemotherapy agents as acting as poison coursing through their veins; support groups members assist new members in understanding that chemotherapy is not poison, but rather needed medicine. Likewise, where a distressed cancer patient might interpret his or her diagnosis as a sign of being punished by God, other support group members may suggest that cancer serves as a positive test of faith to make one stronger.

Existing subcultural theory alone does not identify the mechanism for how support groups draw members into their ranks.  Emotional distress becomes exacerbated when open communication or contact with others becomes blocked or disappears altogether.  The feelings of rejection whether real or imagined may lead the cancer patient to disguise or subvert his emotional distress and attribute unmanageable feelings to himself.  Cancer patient then lose a critical resource for affirming that they can cope and/or are reacting to their situation expectedly (Wortman and Dunkel-Schetter, 1979).  Coping assistance provided within the subculture helps ameliorate the pressure of stress induced by blocked opportunities for success or acceptance (Pearlin, 1989).   In order to cope with feelings of emotional distress and to seek empathetic understanding, people may seek coping assistance from support groups in order to normalize their feelings and to achieve acceptance.  In this way, similar others may be able to offer the best social support (Thoits, 1986).

Labeling theory derives from the symbolic interactionist proposition that an individual’s identity and self-concept are seen as existing only in the context of society.  If self-concepts are simply reflections of what others think of us (“the looking glass self”) then our self-concept can be shaped by the labels that are applied to us.   Deviance from socially desirable norms serves as the means through which the stigmatized enter into the subcultural sphere.  Stigmatization tips the balance towards the attachment and commitment to subcultural groups, making participation in deviant groups or illegitimate/alternative activities more attractive.  Thus, stigmatization of an individual puts that individual at greater risk of behaving according to the label, thereby pushing offenders more deeply into subcultures.  The deviant label may become a self-fulfilling prophecy in which the deviant label only serves to create further deviance.  Or persistent negative reactions to or by others may lead the stigmatized to seek out social support in order to transform socially undesirable feelings into valid and appropriate responses to a stressful condition or situation.

### The Functions and Nature of Social Support

To this point, I argue that viewing support groups as subcultures may facilitate a better understanding of how and why similarly afflicted persons unite to create and sustain an alternative culture to the mainstream. I further suggest that cancer patients, in particular, often experience the effects of a stigmatizing condition and subsequent emotional deviance that prompt them to seek similar others who can provide empathetic understanding. Exactly how social support transforms feelings of stigma and emotional deviance into reasonable and predictable responses remains unclear. In order to examine more closely how social support operates to reduce emotional distress, one must observe the forms and functions social support assumes within a support group of fellow sufferers. I will outline below the state of social support research relevant to health and how social support interactions may work to improved health and emotional well-being of support group participants.

Examining the forms and functions of social support has been the subject of literally hundreds of studies since the early 1970s (House and Kahn, 1985). Populations under study have ranged from otherwise normally functioning individuals to the acutely stressed situated in a variety of personal relationships and contexts (Albrecht and Adelman, 1987; Burleson, Albrecht and Sarason, 1994). The study of social support centers on the notion that social support serves either directly or indirectly (by "buffering" the individual) to improve well-being and health outcomes by reducing stress (House and Kahn, 1985). Although the relationship between social support and stress reduction seems a fairly intuitive one, specifying exactly how social support accomplishes this task has been the subject of considerable debate.

Put broadly, social support consists of helpful functions performed by others on behalf of a distressed person (Thoits, 1986). Although the operationalization of social support has been plagued by multiple interpretations and variations, social support can be categorized broadly by content into three distinct types of supportive functions (Thoits, 1995; House and Kahn, 1985). Instrumental support is the provision of tangible aid or assistance for those in need. Socio-emotional support includes love, sympathy, caring and affection. Informational support refers to advice, feedback, and information that can be used in addressing problems (Thoits, 1995). These three types of supportive functions remain difficult to disentangle empirically; however, they are conceptually distinct enough to be employed as operational definitions of social support (House and Kahn, 1985; Wortman, 1984).

Epidemiologists began the first forays into social support research, trying to link social ties with disease etiology. Cassel (1976) first posited that social support might buffer or moderate the effects of stress on health, subsequently prompting considerable research to substantiate his claim (Berkman and Syme, 1979; Peters-Golden, 1982; Wortman, 1984; Kennedy, Kielcolt and Glaser, 1990; Cohen and Rabin, 1997). The relationship between social support and illness has become a central issue for psychosocial health research, examined in detail from onset to convalescence (Wortman and Conway, 1985; Peters-Golden, 1982; Bloom, 1990; see Cohen and Syme 1985 for review). Among cancer patients alone, social support has been associated with such positive health outcomes as decreased pain, faster recovery, increased physical functioning, better emotional adjustment, and improved immune system functioning (Dunkle-Schetter, 1984). Social support attempts identified by patients as most helpful include emotional support such as expressions of love, understanding, and mere physical presence and tangible assistance such as advice or information (Dunkel-Schetter, 1984; Wortman, 1984; Lehman and Hemphill, 1990). Social support serves as a coping resource that operates indirectly on one’s health or social support may be mediated through one’s coping style, thus indirectly affecting health (Bloom, 1990).

The existing empirical work on social support has generally assumed one of two approaches: social network analysis approach or psychological approach. Social network analysis emphasizes the features of an individual’s social ties and how those ties promote or protect health; the psychological approach gauges one’s subjective sense of actual or perceived support and how it buffers the negative effects of stressors (Burleson et al., 1994). More recently investigations have focused upon the actual face-to-face interactions or exchanges between network members (Burleson et al., 1994; Sarason, Pierce, and Sarason, 1990). Because the process through which social support alleviates stress remains understudied, researchers began to adopt the interactionist perspective as an attempt to redress this research gap.

Symbolic interactionists argue that social support does not take place in a vacuum; one must account for the influence of the relationship between provider and recipient on social support transactions and the context in which such transactions transpire. The notion of social support as a process examines the ways in which supportive transactions influence coping assistance through the reduction of uncertainty and improvement in well-being (Gottlieb (in Albrecht and Adelman), 1987). It permits a more detailed "examination of nuances and tensions surrounding the communication of support" that arises in socially observable dynamics (p. 10, Gottlieb in Albrecht and Adelman, 1987). Therefore, the interactionist perspective on social support analyzes not only how social support is communicated, but also the context in which such communication occurs, and what the outcome of such support may be.

In their survey of epileptic support groups, Arnston and Droge (1987) found that participants most highly rated sharing and reciprocating feelings and thoughts with similar others. They concluded that the "perception of being helpful is the essential component of a social support system" (Arnson and Droge, 1987). This perception of helpfulness maintains the social support equilibrium in the group crucial in promoting feelings of competence and usefulness. Conversely, unidirectional support efforts from a family member or a friend may leave the recipient feeling dependent, inept, or guilty (Coyne, Wortman and Lehman, 1988).

Likewise, Lehman, Ellard and Wortman's (1986) findings suggest two helpful social support strategies that reinforce the findings above: openly discussing one's feelings and connecting with similar others. Their interviews with bereaved spouses and parents showed that the unsolicited dispensation of advice, rude comments, minimization/forced optimism, and encouraged recovery ranked among the top unhelpful behaviors displayed by others, most often relatives of the respondent. The bereaved reported contact with similar others as the most helpful social support behavior (Lehman, Ellard and Wortman, 1986). Although potential support providers appear well intentioned, their inability to provide helpful social support was *not* due to a lack of understanding about what a bereaved person might need. Research shows that in the presence of a seriously stressed person, social support providers' own feelings of vulnerability and helplessness impede effective support (Silver, Wortman, and Crofton, 1990).

### Problems With Social Support

Clearly, not all forms of social support produce a positive influence on health outcomes, and the recipient may perceive even well intentioned efforts by a support provider as unhelpful or negative (Wortman, 1984). Social support can backfire when patients perceived providers' social support attempts as emotionally over-involved, dismissive, inappropriate, or insufficient (Coyne, Wortman and Lehman, 1988). Social support providers have demonstrated a lack of awareness about concerns most salient to the cancer patient such as the patient’s need to demonstrate independence or to express pessimism (McLeroy, DeVellis, DeVellis, Kaplan and Toole, 1985; Williams, 1995). Moreover, research has shown that perceptions of social support as being helpful or unhelpful vary by the potential provider; thus the nature of the relationship between provider and recipient influences the form of social support should take (Dakof and Taylor, 1990).

For example, cancer patients receive mixed messages from others who simultaneously offer comfort and support on the one hand, and project unease and distance on the other. Others may ignore the existence of cancer altogether. The "conspiracy of silence" perpetuated by some healthy social support members may be the result of their feeling vulnerable and uncomfortable by virtue of the cancer patient's status (Wortman and Conway, 1985). In response, cancer patients may find themselves masking their true feelings behind a facade of false cheerfulness and optimism to avoid rejection or hostility from and to receive some level of support from others (Dunkel-Schetter and Wortman, 1982).

Wortman and Lehman found that when faced with victims of life crises, significant others felt vulnerable and helpless themselves. Uncertain how to react and fearful of reacting inappropriately, support providers distance themselves because they worry about causing further harm to the victim. Without personal past experience to guide them, support providers may have too narrow an understanding of what a victim truly needs and may be overwhelmed by the extent of the victim’s plight (Wortman and Lehman, 1985). The irony underscored by researchers (Wortman, 1984; Dunkel-Shetter and Wortman, 1982) is that the more intense the individual’s support needs become, the more likely beneficial social support from family and friends will evaporate. “Consequently, individuals in greatest need of support may be the least likely to get it” (p. 464, Wortman and Lehman, 1985).

For social support to be effective it should alleviate some of the emotional and physical demands placed on the cancer patient rather than create more stress for the patient and possibly undermine emotional well being. Peters-Golden (1982) compared the results of received social support among cancer patients and perceived social support among healthy individuals. Healthy individuals reported perceiving a dense network of supporters at their disposal in the event of cancer whereas cancer patients reported the non-materialization of such social networks during their illness. Cancer generates considerably more fear among the healthy than other diseases as demonstrated by the reactions of significant others (Peters-Golden, 1982).

An important corollary to the examination of miscarried or missing social support is the normative expectation held by others regarding the magnitude or duration of distress. Most people have little experience in assisting others in the midst of a life-threatening crisis, and consequently may have completely erroneous expectations about how intensely an individual should react under such circumstances (Wortman and Lehman, 1985). Wortman and Dunkel-Schetter (1979) theorized that the effective provision of social support might conflict with a provider’s understanding of appropriate behavior and own feelings of fear and aversion. Consequently, interactions with a distressed victim might lead to forced optimism and avoidance of the person. Intentionally or unintentionally suppressing the magnitude or duration of a stressed individual’s emotional responses implicitly communicates that his or her feelings are deemed incorrect or inappropriate for the situation.

In contrast, the process of sharing one’s cancer experience with similar others can potentially reduce social isolation, uncertainty, and stigmatization (Dunkel-Schetter and Wortman, 1982). Similar others theoretically should be ideal providers of social support and coping assistance since they, unlike other network members, are not threatened by the possibility of developing the condition themselves. Fear of death and uncertainty about long-term survival could be reduced through the exchange of others’ experience and knowledge about the disease. Support groups provide a community of empathizers all of whom have experiential knowledge. Their experience translates into expertise that can be shared with the other members of the group. Fellow cancer patients may not misinterpret the venting of anger or fear as coping poorly, but rather as an effort to clarify negative feelings. Likewise, cancer patients among similar others may not feel the need to maintain a cheerful presentation of self so as not to engender the disapproval of healthy others (Wortman and Dunkle-Schetter, 1979). But even these same supportive efforts encountered in support group participation have the potential to backfire producing even greater distress or harm as elaborated below (Dunkel-Schetter and Wortman, 1982).

### Social support within cancer support groups

David Spiegel's groundbreaking research in the early 1980s on support groups for women with metastatic breast cancer demonstrated that the opportunity to express oneself openly and to receive coping assistance led to improved adjustment and adaptation when compared to a control group (1981). However, a major limitation of Spiegel's support group findings (characteristic of social support and cancer research generally) is the lack of specificity in determining just how these supportive processes operate to decrease distress and fearfulness. In an attempt to shed light on social support processes among cancer patients, Taylor et al. conducted an empirical investigation into social support needs and cancer support group participation (1986). Given that previous research found a positive relationship between social support and psychosocial and physical improvement within support groups overall, Taylor et al. assessed the perception of support from other sources among current support group participants. Presumably unmet social support needs from other sources of support would galvanize patients into seeking support from similar others.

Although family and friends were found to be helpful, about half of the respondents reported a need to talk more openly (Taylor et al., 1986). Group participants were only slightly more likely than non-participants to report cancer related worries, but were significantly more likely to draw upon multiple sources of social support. Negative experiences with health care professionals were significantly more likely to lead cancer patients to joining support groups than deficient social support from family and friends (Taylor et al., 1986). The lack of significant differences between participants and non-participants coupled with an only modestly increased reporting of cancer concerns among participants lead Taylor and her colleagues to issue only a lukewarm endorsement of support groups. They suggest those who turn to support groups are more likely to seek help from a multiplicity of sources who likewise meet their needs. Although the researchers attempt to address the question of why cancer patients join support groups, they admit that the kinds and effectiveness of social support offered by similar others still remain unanswered (Taylor et al., 1986).

Ten years later, Helgeson and Cohen conducted an extensive review of the intervention conditions under which social support facilitates positive cancer adjustment (1996). Their analysis upheld the findings of past research that showed individual perceptions of social support as helpful or unhelpful depending on the provider and function (Coyne, Wortman, and Lehman, 1988; Dakof and Taylor, 1990; see Wortman and Lehman, 1985 for review). For example, family, friends, and caregivers with the best intentions may make an already stressful situation worse by offering informational support. However, the same kind of support when provided by a health care professional was usually considered helpful (Helgeson and Cohen, 1996). Despite an overall methodologically flawed body of literature, the correlational research overall showed a strong connection between emotional support and adjustment (Helgeson and Cohen, 1996).

Because correlational research appears to demonstrate that cancer patients have support needs unmet by their existing networks, Helgeson and Cohen turned their attention to the intervention research involving peers to assess support group participation and adjustment. Interventions studies involving similar others were educational-, informational-, or discussion-based, or were a combination of discussion and education. Although group discussion studies proved to be too inconsistent in design to draw any conclusions definitively, the evidence was that they appeared to be less effective than suggested by the descriptive and correlational research (Helgeson and Cohen, 1996). Educational interventions, on the other hand, met or exceeded the level of effectiveness found for group discussions to the surprise of the authors.

Thus, evidence shows that generally cancer patients want the opportunity to talk with similar others; but, in reality, they report mixed feelings when they actually do. Helgeson and Cohen speculate that like any other source of support, the intended recipient may not always appreciate social support proffered by group members, depending on the content or the source of the support and the perception of such social support. Educational interventions may feel “safer” emotionally than group discussion because ostensibly participants are there for information and not necessarily for emotional intimacy. Psychological defenses such as denial or optimism may be punctured by the experiences of other cancer patients with more serious circumstances, exacerbating distress (Dunkel-Schetter and Wortman, 1982). Feelings may be more difficult to normalize when faced with someone with a poor prognosis or a different kind of cancer (Helgeson and Cohen, 1996).

In order to rectify the dearth of methodologically sound data on cancer support groups, Helgeson et al. conducted their own study of educational and peer discussion support groups for women with breast cancer (1999). Participants were randomized into one of four treatment groups: education only, discussion only, education followed by discussion, and no treatment. Patients in the education only group reported enhanced self-image while patients in the peer-discussion group only reported feeling more anxious in the company of sicker peers who shared the same diagnosis (1999). Women in the peer discussion group compared themselves negatively to others regarding lymph node involvement (a major predictor of survival) and chemotherapy side effects, particularly hair loss (Helgeson et al., 1999). Furthermore, group interactions appeared to negatively influence relationships with other social network members because, the authors speculate, their perceptions of support from family and friends changed for the worse. The authors admit that an eight-week peer discussion group may not have been long enough to overcome some of the problems described above. But more importantly, Helgeson and her colleagues concluded “we may still be at the point where successful intervention studies raise more questions than they answer (p. 23, 1999).”

Gottlieb contends that social comparison “lies at the heart of social support’s stress mediating role (p. 309, 1985)”. Group participants use others as comparison models to determine their relative well being and functioning. Taylor found in her research on women with breast cancer that they typically described themselves as coping better regardless of the type of contact with the comparison target (1982). Within cancer support groups, social comparison may become a more finely graded process in which group members who share a cancer diagnosis in general may perceive similarity only along certain stressful, cancer-related dimensions. Although the shared experience of cancer may unite members in most instances, particular instances may arise whereby unsolicited offers of social support may be rejected if the group member fails to perceive adequate similarity regarding a particular stressor (e.g., hair loss support between men and women).

Social comparison, both upward and downward, appears to evoke both positive and negative responses, regardless of the point of comparison (Buunk et al., 1990). In their comparison of cancer and marriage populations, Buunk and his colleagues found that upward comparisons among a cancer (stressed) population were more likely to lead to positive affect whereas in a marriage (normal) population the opposite proved true. Their findings also support the idea that individuals strive to maintain a positive outlook through blocking negative information rather than acquiring positive information. Personal control lost to the uncertainty surrounding cancer may be regained to some degree through the control of negative information in the social comparison process (Buunk et al., 1990). In other words, the illusion of control related to cancer may be maintained through the avoidance of negative perceptions generated by others or possibly by avoiding similar others altogether.

Wortman and Dunkel-Schetter (1979) suggest that cancer patients may obtain clarification and support through a combination of selective social comparison, sympathetic listening, and coping assistance regarding their condition. Coping assistance refers to the actions of others in managing an individual's stressful situation (Thoits, 1986). Similar others may actively participate in the reducing the stress and anxiety related to cancer by changing the meaning of the situation, changing the emotional reaction to the situation, or changing the situation itself (Thoits, 1986). Others facing the same stressful situation are in a particularly useful position of validating feelings that appear improbable or confusing to healthy outsiders because they possess what Thoits calls "empathetic understanding" of the problem, a crucial condition in the search and receipt of effective coping assistance. Empathetic understanding should facilitate the greatest likelihood of coping assistance being perceived as effective (Thoits, 1986).

Not just any cancer patient makes an acceptable comparison target; those who seem to be managing too effortlessly or who seem excessively distressed may be rejected for their guidance or role-modeling (Thoits, 1986; Dunkel-Schetter and Wortman, 1982). Thoits argues that the need to be reassured about the appropriateness of one's own reaction supercedes the need to compare one's self for guidance (1986). Whether this is true among cancer patients cannot be determined from the evidence provided by the two studies conducted on peer support among cancer patients (Helgeson and Cohen, 1999; Taylor et al., 1986). People's requirements for coping assistance may change as the demands of the illness change. The situational demands of cancer vary by disease stage and progression (e.g., physical deterioration, cancer remission) and one's coping strategy must adapt accordingly, which may include a shift in social comparison targets. Empathetic support arises from situational similarity, and if the situation changes so will perceptions of efficacious sources and kinds of coping assistance.

In sum, people draw upon a multiplexity of behaviors and sources of support in coping with cancer rather than rigidly following one particular way, and their support needs invariably change over time (Taylor et al., 1986; Dunkel-Schetter et al., 1992). In joining a support group, conceivably feelings of stigma and emotional deviance are more likely to be validated because a subset of cancer patients voluntarily utilize these groups as a support resource. Coping assistance offered by similar others in support groups may be reassuring in theory, but disconcerting in reality. This discrepancy appears may help to explain why firm evidence showing the beneficial effects of cancer support groups remain ambiguous or mixed. It would be unreasonable to expect any single support strategy to be efficacious across all situations since personal situations are bound to change (Thoits, 1995).

### Conclusions

To summarize, this dissertation will show that by reconceptualizing cancer support groups as a subcultural phenomenon we may better understand how cancer patients manage their perceptions of stigma and emotional deviance through the exchange of coping assistance and social support. Although to date no empirical or theoretical research exists to suggest a conceptual bridge between subcultures and support groups, I will provide evidence to substantiate that cancer support groups do contain key features and functions of subcultures based on direct observations of support groups. As noted earlier, subcultures may be characterized as a group of persons who band together to create and sustain a body of shared cultural knowledge distinct from society at large. Likewise, support groups use a distinct ideology, values, and norms to attract similarly situated individuals and through face-to-face interaction transmit a particular understanding or explanation of their situation.

Further, I will argue that the perceptions of stigma and emotional deviance motivate persons to join a cancer support group. Stigma reduces the quality and quantity of available social support, resulting in distress caused by insufficient or negative responses. The inability of family, friends, or employers to respond appropriately or favorably to the needs of a cancer patient may lead to the cancer patient's perception of being shunned or dismissed. Moreover, individuals unable to acquire clarification or understanding from others may experience unrelenting feelings of anxiety or distress that causes them to perceive themselves as emotionally deviant. As Shinn, Lehmann and Wong suggest "one person's distress can become another person's stressor and defeat the support process" (p.59, 1984). An emotional deviance approach can provide an explanation of how people with cancer may perceive themselves as deviant or stigmatized, and subsequently turn to similar others for help.

Support groups provide contact with similar others who may offer the best social support as persons who understand the problem first hand. By finding a support groups, the cancer patient makes an active attempt at augmenting coping and social support resources to overcome the limitations imposed by stigma and support availability and seek legitimization or validation of their emotional distress. The ideology and norms promulgated by a support group work to counteract the poor treatment by others through the provision of informational and/or emotional support.   Support groups augment or, in some cases, replace one's social support contacts in everyday life (Gottlieb, 1985).

In order to verify that cancer support groups contain key features and functions of subcultures, one must directly observe those groups in a naturalistic setting to document such evidence. Observing support groups in action provides evidence for specifying how feelings of stigma and emotional deviance may be reduced or replaced through the exchange of social support and coping assistance.  Using detailed qualitative data, I plan to explore the contexts in which coping and support-giving processes unfold.  In particular, I intend to clarify the conditions under which particular types of support are likely to be offered by similar others, and which kinds of coping assistance may be judged as beneficial (or detrimental) by the recipient (Wortman and Lehman, 1982).   In this way, my study will authenticate how support groups function like subcultures into how people manage a highly stressful situation in a mutually supportive group setting.

# CHAPTER II

# RESEARCH METHODS

## Restatement of the Problem

The primary goals of this research were to marshal evidence that support groups contain key features of subcultures, to understand how participants arrive at cancer support groups, and to show how they function to reduce or occasionally exacerbate participants' reported feelings of stigma and emotional and cognitive deviation. In order to accomplish these tasks, one had to observe cancer patients interacting in a naturalistic setting. To justify how support groups may be viewed as subcultures, I illustrated the key features of support groups consistent with the definition of subculture. I also described how respondents' interpret their experiences with stigma and emotional deviance that lead them to support groups. Finally, I recorded the transactions of social support and coping assistance that occur between support group members. I also described the conditions under which particular kinds of social support and coping assistance get exchanged and the forms they take in those transactions. With these questions (or goals) in mind, I chose to rely on participant observation research in order to answer the research topic.

### Participant Observation Research

I selected the participant observation method because the nature of my research question is dependent upon the interactions, interpretations, and observations of support group members in their own voices. No other method would allow me to capture these processes as they spontaneously occur in the course of social interaction. Participant observation offers the opportunity to observe social interactions and processes as they unfold over time in their natural setting (Jorgenson, 1989). This approach provides insight into participants' understanding of experiences and interpretation of meanings that shape how they look upon the world. One's subjective perception of reality may be exposed through observing the manipulation, obfuscation, or negotiation of everyday occurrences and interactions in daily life (Jorgenson, 1989).

The key characteristic of this particular qualitative method is "observation through regular participation in the naturally occurring activities of social groupings" (p. 351, Emerson, 1981). Through observation sustained over time, the researcher can gain an understanding of behaviors and feelings as filtered through the participants' perspective. In examining the details and nuances of social life, one may gain richly descriptive or "thickly described" data about social interactions (Geertz, 1983). Thus, qualitative participation observation does not produce data with "objective" meaning; instead it captures data that reflects how participants construct social meanings in their interactions with each other (Emerson, 1981).

In-depth interviews would have given me the opportunity to question support group participants about their subjective reactions, interpretations and understandings. Weiss (1994) argues that in-depth interviews can project the feeling of "being there" because interview subjects present events as they experienced them, expressed in their own words and in their own imagery. However, my primary focus was to capture the spontaneous interactions between support group members *as they happened* rather than members' reconstruction of events or problems after the fact. Participant observation methods are well suited to researchers interested in investigating process-oriented events that would otherwise be limited to the participants involved in those particular circumstances. Since this dissertation is concerned with providing a comprehensive picture of behavior (verbal and non-verbal) that occurs in a particular setting over a long period of time, participant observation is a more appropriate research method than in-depth interviews.

Unusually, I began collecting data prior to formulating the current research questions of my dissertation. In fact, the current research questions of my dissertation emerged from my informal impressions as the data collection process progressed. When I began first my research in 1998, I was initially drawn to the participant observation method because I wanted to observe social support transactions as they unfolded in a natural setting. Fortunately, the questions currently asked in my dissertation can be addressed with these same data because I took detailed field notes on the sequence of events and interactions between participants at every support group meeting. Because the nature of participant observation is to capture the full range of occurrences in a given setting, the level of detail yielded by this method provides a certain degree of flexibility in selecting the processes on which the researcher might focus (Bailey, 1994).

### Methodological Criticisms of Participant Observation Research

Shaffir and Stebbins introduce their book on qualitative research with the following observation: "fieldwork must certainly rank with the more disagreeable activities that humanity has fashioned itself" (p. 1, 1991). One must learn to balance any inconvenience and awkwardness on the researcher's part in return for being permitted to participate in the group (p.4, 1991). Clearly the goal of any participant observer is to record the social interaction and capture firsthand the symbolic meanings as understood by those observed. The researcher must be able to represent the particular setting under study to readers lacking any direct familiarity with it (Emerson, Fretz and Shaw, 1995).

A major criticism of participant observation research is its lack of replicability, a key characteristic of quantitative methodological approach. Replicability refers to the extent to which a comparable population will present the same "answers" to a research question, given the use of the same study methods (Fowler, 1993). In qualitative research, no objective criterion exists against which answers can be compared; thus, there is no way for answers to be independently verified (Fowler, 1993). Participant observation makes replicability nearly impossible because no two researchers will capture the vast amount of information in a field site in the same way or interpret it in the same ways. Although no field site or participant interaction can be perfectly replicated in subsequent studies, substantive theoretical findings should be replicated across situations, sites, or cases. My study aimed to illustrate how cancer support groups function like subcultures and how group members manage their stigma and emotional deviance through group mediated social support and coping assistance. While the specific way in which one member may offer coping assistance to another member may be particular to my study, the general process of coping assistance within a stigmatized or emotionally deviant group may be found in other similar situations.

This sort of theoretical replicability is augmented by the fact that my study focused on cancer support groups rather than on support groups for equally stressful, but rare conditions or for specific types of cancer. Although I chose to focus on cancer because of my interest in what people do to manage a highly stressful and stigmatizing condition, I also chose cancer support groups because the increasing frequency with which they may be found in cities around the US. Had I focused on one particular type of cancer, one could easily question whether or not findings could apply to cancer groups in general. Cancer affects three out of four families in the United States and constitutes a major life stressor that impacts millions of Americans each year (Taylor et al., 1986). Cancer is a particularly unique illness because it contains aspects of both an acute and chronic illness that may drag on for years and years. Despite the prevalence of cancer in our society, misunderstandings about psychosocial adjustment and physical condition still persist, perpetuating the emotional and cognitive deviance and stigma felt by those diagnosed. The subsequent need to evaluate the provider, type, and conditions under which effective social support and coping assistance may be exchanged have potentially far reaching consequences for the millions of people affected by cancer.

Generalizibility in quantitative studies refers to generating a sampling frame whereby respondents are selected by an objective and probabalistic mathematical procedure to ensure representation. Participant observation studies, on the other hand, are characterized by small numbers of cases and thus raise the question of whether or not generalizibility is a serious methodological shortcoming. Qualitative researchers must balance breadth with depth with the hope that by focusing limited resources on a smaller sample a greater level of detail may be reached. The intensive nature of participant observation studies "requires that they be conducted over a much longer period of time than a survey" (p. 245, Bailey, 1994). Despite usually having a small number of support groups overall, this qualitative method offers an abundant data source of detailed social processes experienced within each support group.

The support groups I selected for observation in this dissertation represent a small, non-random sample of cancer support groups in general. In an effort to redress the limitations imposed by my small sample size, the sampling strategy I used maximized variation in support group structure (professionally led and lay led) and ideology (emotion and information focused) in order to enhance the theoretical generalizibility of my findings. I believe that the level of detail obtained through the use of participant observation methods provided a more complete representation of the social processes at work in cancer support groups than would be possible through the use of other research methods.

### Subject Reactivity in Observational Research

Subject reactivity encompasses the ways in which a study participant's behavior changes in the presence of an observer (Emerson, 1983). Thus a major criticism of participant observation research is that observers' findings cannot capture everyday life in a field site without capturing the effects they artificially introduce by their presence. The implication is that study participants will behave differently than they would have if the researcher had not been there. Emerson argues that "field work is unavoidably interactional in character, and the field worker is necessarily consequential for those studied" (p. 365, 1981). He further suggests that the solution does not lie in reducing or systematizing interactions in the field, but in sensitizing oneself to the perceptions of treatment by others (Emerson, 1982). In my observation of cancer support groups, I certainly may have produced effects in my data that are the result of subject reactivity. Although I assumed a largely non-participatory role, my mere presence may have influenced the behavior of support group members.

Despite the potential for harmful effects, researchers argue that subject reactivity likewise may produce effects that may be useful for observers. The interactions an observer has with those studied can become a source of data about the setting rather than a contaminant (Emerson, 1981; Emerson, 1983). Arguably critics may say that in an observer's company any differences documented in a participant's behavior may not be a "real" difference, but a reaction to a change in the researcher's behavior (Katz, 1983). As long as the observer is checking for the alterations in the setting he may cause, Katz argues that responses to the observer are no more problematic than any other interaction and comprise substantive data (Katz, 1983).

For example, in Lawrence Weider's fieldwork experience at a half-way house for paroled ex-addicts, he learned the "convict code", an implicit normative structure that shaped the kinds of interactions he could expect to have with the residents (1983). The code necessitated that residents demonstrate their loyalty to each other through the distrust of the staff and the avoidance of appearing to be a "snitch", or they could face serious injury or death. Through his conversations with residents, Weider learned what kinds of questions he could reasonably ask and not ask by virtue of his role in the half way house. Weider's role as a researcher seriously limited the breadth of research he could undertake in that particular setting. However by invoking the code in reaction of Weider's presence, residents revealed the boundaries of their behavior and conveyed rich information about themselves and their culture.

In order to minimize reactive effects, researchers may be tempted to assume covert or unobtrusive identities, but these two issues only increase the potential for subject reactivity (Katz, 1983). When a researcher assumes a covert role, he aims to portray himself as an authentic member of the setting and/or to gain entrance into a closed situation. In misrepresenting his true identity, his need to manage his "front" is pressing and his sensitivity to reactive effects is impaired (Emerson, 1981). Unobtrusive observers avoid formal roles altogether and attempt to be as passive or neutral as possible in gathering data. Clearly, unobtrusive observers deny themselves the emotional and subjective insight and understanding that comes through interaction (Emerson, 1981).

Rosalie Wax (1971) notes that immersion into the field is always a joint process, mutually negotiated by the fieldworker and the members of the group or culture being observed. The fieldworker cannot expect to be absorbed as a "native" group member who can instantly achieve a rapport and acceptance "as one of them", according to Wax (1971). Realistically, the field worker initially can expect to experience feelings of being in "almost total social limbo" until the hosts allow or invite the researcher into their world or at least "give [her] a place to stand" (p. 192, Wax, 1971). The degree of participation permitted the field worker depends on the degree to which the hosts will tolerate the presence of an outsider. In essence, the group, not the field worker, defines the terms of membership. The degree to which a field worker is and can be accepted as a member may inherently limit what aspects of group life she may observe.

The field worker must not confuse her inclusion as a participant with the assumption of a native identity, dubbed by Wax (1971) as the most "egregious error" (p. 195) made on the part of the field worker. Wax recommends that a successful researcher will remember not only who she is, but also who the hosts are. The fieldworker should express sensitivity and respect for her hosts by occupying a more deferential role until invited to do otherwise. The assumption of a native identity on the part of the researcher does not mean that her hosts will ever perceive the researcher as anyone who closely approximates them. Attempts at authenticity may only backfire, eliciting ridicule and resentment. Despite her presence as an outsider, the researcher may serve in a functional role perceived as mutually helpful and acceptable. Wax notes that researchers most often do not neatly fit into pre-existing roles, but instead develop hybrid roles in conjunction with host members. The value of participant observation comes from the perspective gained by the adoption of such roles, not from the adoption of a pseudo-native identity (Wax, 1971). I believe making my identity and intentions known as a graduate student researcher provided justification for my presence and gave me authenticity in a role that otherwise did not exist within the support groups.

Raymond Gold (1953) delineates four theoretically possible roles for the sociological field worker, each role facilitating a means of social interaction through a corresponding set of behaviors. In choosing a role in the field, one must strike the balance between one’s true identity and the best means of studying society (p.223, Gold, 1953). In cancer support groups, I assumed the participant as observer role in which group members were fully aware that I was graduate student studying how cancer support groups functioned. An informal, participatory role as a graduate student, I believe served as the least disruptive means of observing support groups and gave me the best access to collect information on the support group process. After attending the groups over a period of several months, I began to grow more familiar to group members and I perceived them becoming more comfortable with my presence. Because group participants knew up front who I was and what I was doing, I would not be mistaken for someone with cancer and subsequently treated inappropriately as one of them. I was able to observe formally within the group setting and eventually became included informally through occasional casual conversations before and after group meetings.

### The Field Sites and Gaining Access

In August of 1998, I contacted the local American Cancer Society chapter of Volusia County, Florida to inquire about on-going cancer support groups in the area. A volunteer gave me the name of Becky Blevins, an oncology nurse at Halifax Medical Center in Daytona Beach, Florida. In addition to working as an oncology nurse in the cancer center, Becky Blevins also had a master's degree in oncology counseling and served as the facilitator for an afternoon support group that met twice monthly for an hour and a half. She also provided family and one-on-one counseling for cancer patients in need, often for the newly diagnosed or terminally ill. In addition to Becky there was another counselor, David Blenco, who was primarily based at smaller medical facility to the south, Bert Fish Medical Center in Port Orange. Working as a hospital-based social worker, he facilitated a monthly melanoma support group that had been meeting for over year to my knowledge. Unfortunately, I only observed a single melanoma group because two months later the group disbanded due to the deaths of several members.

After having attended the general cancer support group at Halifax Medical Center, I learned from Becky about a breast cancer support group that met at a satellite location of Halifax Hospital to the south. As a representative of the hospital, Becky attended the breast cancer group although she did not function as a facilitator. The first evening I attended, Becky introduced me to Laura, the support group leader and a breast cancer survivor, explaining to her that I was interested in understanding the dynamics of support groups. She quickly introduced herself to me and turned her attention immediately to other women waiting around her to ask her questions. Once Laura called the meeting to order, she introduced herself first as a breast cancer survivor and then introduced me to the group. “We have graciously and gratefully invited Lori to be a part of our meeting tonight," said Laura to the group. This group was much larger than the general support group (50 or more members) and had had a more diversified format than simply sitting around a table talking like the Halifax group. This group did not always hold a typical meeting like the one that evening. They carried out fundraising activities throughout the year to raise money for breast cancer research and to supplement a local hospital fund for needy patients.

About two months before I moved from the area, I heard Becky discussing a breast cancer support group for terminally ill women that she led on a weekly basis. Although I immediately expressed a strong interest in observing that group, she thought my presence would be too uncomfortable for the group members, many of whom were close to death. I gleaned that these women with metastatic breast cancer felt exceedingly more anxious and vulnerable than the general cancer support group I observed. Becky wondered aloud how much longer she herself could keep working in oncology after facilitating such an "emotionally draining group". One older female participant in the Halifax group expressed an interest in having Becky and me talk more personally about ourselves as other cancer patients did. But clearly that would not have been appropriate for either of us.

In Nashville, Hillary Forbes, the assistant director of the Vanderbilt Women's Center contacted me regarding an upcoming cancer support group starting on campus for students affected by cancer. She gave me the name of the facilitator of the student group, Rhonda Venable, a counselor at the Vanderbilt Counseling Center. In order to meet Ms. Venable, I attended a breast cancer lecture and book signing. There I met Rhonda who gave me the name of Felice Zeitlan, the director of Gilda's Club - Nashville. Gilda's Club is named for the comedienne, Gilda Radner of Saturday Night Live fame who died of ovarian cancer several years ago. Gilda's Club is a non-profit organization that offers free support services to cancer patients, their friends, and family in select cities around the US. I soon learned that several of the major hospitals in the metropolitan Nashville area no longer ran support groups for cancer, instead referring patients to Gilda's Club. When I contacted Baptist Hospital regarding a support group for women with metastatic breast cancer (one of the few hospital support groups remaining), they informed me that I would not be permitted to observe this group. Like Seaside, the facilitator felt the women were too emotionally fragile.

Initially, I was interested in exploring the differences between lay and professionally led support groups, so I strove to gain as much diversity in my groups (lay vs. professionally led; information vs. emotionally focused) as possible. I was particularly interested in accessing prostate cancer groups not only to counterbalance the overwhelming female representation of breast cancer groups, but also because research suggested men gravitated towards informational support groups. Furthermore, researchers have noted that women outnumber men in cancer support group participation four to one (Cella and Yellen, 1993). While in Florida, I attempted to access to the only existing prostate cancer group in my area, called Man to Man (an American Cancer Society sponsored program). Unable to reach anyone by phone and eager to sample the group, I attempted to introduce myself to the leader before one group meeting, the time and date of which I found in the local newspaper. Upon meeting me, the leader promptly escorted me outside the building saying because women did not participate in this group and that my presence as a woman (and thus as a researcher) would not welcome. These men, he explained, intentionally met without the presence of women so they could talk frankly and candidly about their condition and its attendant problems. A major side effect of prostate cancer treatment is the impairment of a man's sexual performance, an intimate matter for obvious reasons.

I contacted the head of an international prostate cancer group with a chapter in Nashville called US-TOO, Eldon Boone. A retired Baptist minister and prostate cancer survivor, Eldon took responsibility for organizing and maintaining a monthly support group for men and their partners. He worked in conjunction with one of the member's wives to maintain a phone and e-mail list to distribute the organization's newsletter, informing fellow members about meetings and topics. Unlike the Florida group, I was granted access to this group because most men brought their wives or girlfriends and their presence was felt to be conducive to men's participation. Although in its literature US-Too purports to advocate, advise, educate and publicize, this group seemed primarily informational in focus having speakers at each meeting to address the informational needs related to particular facet of prostate cancer. During the group, Eldon opened and closed the group with his remarks (often providing a little homily) as well as introduced the speaker. Baptist Hospital provided refreshments in the hall outside the conference room where people milled before and after group. This group met in a conference room of one of the professional buildings associated with Baptist Hospital.

Thus, over the course of two years, I observed three general cancer support groups, a breast cancer support group, a melanoma support group, and a prostate cancer support group. Three groups met monthly, one group met alternate Thursdays, and two groups met weekly. Because I planned to observe all the participants attending any single support group meeting, I did not undertake any formal recruiting procedures. I consulted with the group facilitators beforehand, all of whom verbally granted me their consent to attend their support groups. I collected data from August 1998 to May 2000 producing 163 pages of single spaced notes over the course of roughly 62 hours in the field[6]. With the exception of the melanoma and the breast cancer support groups, I followed the groups for one year. The number of attendees at any given support group meeting varied from month to month. For example, one breast cancer support group ranged in size from 20 to 100 people, depending on the topic for that particular meeting. However, most groups were fairly small in size, averaging five or six participants.

One potential bias introduced into my research concerned the kinds of cancer support groups to which I could gain access. I would make a telephone call to a support group facilitator or support organization director to request permission to attend the support group that he or she ran. I made available the IRB synopsis of my study not only to provide background information about my study, but also to confer some academic legitimacy on my research. I would follow up a few days later with a telephone call to arrange a meeting time to discuss my observing support groups further with the facilitator.

Whether or not I gained access to a cancer support group depended entirely on the willingness or interest of the facilitator in having an outsider join his or her support group. Rather than meet with me personally, four facilitators told me over the telephone that they would ask the permission of all the group members at the next meeting and get back to me regarding their decision. In the case of Gilda's Club, I heard back from the two facilitators, but in the other

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[6] This is an approximate number because I would go early and leave late in order to capture conversations before and after group. All groups met for an hour and half with the exception of the Gilda's Club groups that met for two hours.

two cases I heard nothing, which presumably meant no. Four others outright rejected the possibility of having me present my research goals in the group often for reasons not entirely made clear to me. In total, I contacted twelve facilitators, half of whom permitted me to observe their support groups. Facilitators served as gatekeepers regulating who joined their groups and who did not. Moreover, they also limited the range of support groups I was able to sample.

Prior to my entering any support group, the facilitator relayed my request to observe the support group to the members and obtained the their private votes. Voting without my presence allowed individual members to avoid feeling pressured into being observed. Then the support group facilitator informed me whether or not the group as a whole would allow me to observe. At that time, I was permitted to observe the group

### My Role in the Field

Beginning in the summer of 1998 through the fall of 2000, I wrote detailed field notes based on the observations of six different cancer support groups in two states. While participating in the group, I interacted with cancer patients, making casual conversation, offering sympathetic comments, or simply listening to others. At no time during my immersion in the field did I attempt to portray myself as anything but a graduate student studying how support groups work. Each time a new member arrived, regardless of the group in which I happened to participate, I introduced myself and clearly indicate that I did not have cancer, but was in fact a graduate student. In this way, I tried to delineate a clear and different role for myself apart from those occupied by the participants or the facilitator. From time to time, I offered my assistance to group members trying to research their own cancer over the Internet or through Medline medical database. Because I did not have counseling or an "experiential" understanding cancer, I thought I could at least offer my assistance as an informational resource. In this way I, too, served as functioning member of the group, fulfilling my duties as part of the implicit code of social support reciprocity among group members.

My field notes included activities, interactions, emotional responses, and, at times, the physical appearance of the participants. Additional activities recorded in my notes included educational lectures by guest speakers, and less infrequently relaxation exercises. As a participant observer, I made mental notes of all interactions that occurred in my presence before, during, and after group among group members, their families, friends, and facilitators. Emotional responses during a support group session ran the gamut from serious distress to anger to elation often regarding one's disease progression or cessation. Weight loss, wigs, skin discoloration, and facial swelling all served as fairly reliable indicators of persons in active treatment for their cancer. Noting these aspects of physical appearance occasionally helped me to corroborate my hunches about a particular person's disease progression or emotional state.

I also recorded my own reactions to events during the group and hunches about participants or occurrences, as appropriate. The information recorded in my field notes followed as closely as possible the group discussion as it unfolded, noting transitions and reactions that altered the course of conversation. I paid close attention to the conversation even when the discussion drifted to non-cancer related subjects, trying to remember the specific words that were spoken. Generally, my notes began when I arrived in the field, usually the building in which the group was conducted. I included conversations prior to group, described the events in sequences, and concluded my mental and actual note taking when I left the building.

My role as a graduate student restricted the kinds of comments I felt I could make. A few of the groups I observed had previously permitted a student to observe, generally an undergraduate completing a course requirement. Although I was an advanced graduate student working on my doctoral dissertation, most group members did not differentiate me from any other undergraduate student who had been present. I attempted to record all the interactions and behaviors of members present in a given support group to the best of my recollection. When I arrived home after each group, I began to record my field notes as soon as possible. Naturally there are times in my observational notes where I could not recall a particular conversation shift that demonstrated how the conversation topic or speaker had changed.

Initially I planned to audiotape support groups sessions if deemed acceptable by the support group facilitator. Prospective respondents were told that I would be recording their interactions for the purposes of examining how support groups facilitate coping and social support as well as manage stress induced by their cancers. I only audiotaped cancer support group sessions with the consent of all participants. Respondents indicated whether or not they grant their permission to be audiotaped. I assured them that anonymity would be maintained through the use of pseudonyms throughout my notes on support group interaction and in the transcription of audiotapes from group sessions and in-depth interviews. In the event that a support group member would become uncomfortable during the taping of a group session, I would immediately desist from audiotaping the group.

I quickly realized after a few group meetings that audiotaping produced tens of pages of notes requiring several days of transcription by me, a very inexperienced transcriptionist. Although recording an entire support group session would have provided me an exact and therefore more accurate accounting of the conversation among the participants, it did not seem practical given time restraints and my abilites. Moreover hiring a transciptionist would not have been possible because he or she could not have been able to identify and thus attribute comments to the correct person. Because I knew the members and their respective voices only I could have been able to correctly transcribe any audiotape recordings.

### Researcher Biases Introduced by the Participant As Observer Role

Given that I was a graduate student participant observer, I unavoidably introduced bias into my research. My role as a person without cancer, a “dissimilar other” so to speak, excluded me from more intimate interactions with group members and from contact outside the support group itself such as phone calls or more personal gatherings. I could have in no way pretended that I had cancer; group members could have employed any number of strategies to uncover my non-cancer identity. Cancer patients and survivors often saw each other regularly at doctors' appointments, usually during chemotherapy or radiation. Names of health care providers were routinely exchanged, and their regimens compared and contrasted among support group members. Furthermore, short of being a health care professional myself, I could have never possessed the same medical vocabulary as a person with cancer who routinely invoked names of procedures, medications, chemotherapies and adjuvant therapies and side effects. Even pretending to be someone with an ill family member would have precluded me from attending support groups for persons with cancer since separate support groups existed for affected friends and family members.

At the time I entered the groups I was a complete stranger to the first hand experience of having cancer. Although I had volunteered in a cancer center for a year and worked for the American Cancer Society’s Behavioral Research Center for two summers, I was not intimately familiar with the routine challenges and fears that face people with cancer on a daily basis. While I do not think that my lack of first hand knowledge of cancer affected the groups' willingness to accept me and interact with me, the fact that I did not have cancer made it more difficult for me to understand and interpret certain situations. Group members interacted with one another elsewhere, such as doctors' offices or their homes; however, I only saw group members during the support group meeting time. Occasionally, an event or problem that happened outside of group would be discussed during the group meeting and I felt as though I was the only one who did not know what had happened. I also felt this way when current members provided updates on former or long absent group members whom I did not know personally. I could usually get the gist of what happened by listening to the discussion of others and asking a few questions, but I am not certain I always asked the correct questions or whether my asking questions was appropriate. I quickly realized that I was not always in tune with the rest of the support group members' lives and understanding these other events was important for understanding their interactions in group. Perhaps being more in tune with the other parts of their lives, either through socializing or receiving medical treatment, I would have had a fuller understanding of their lives and events that affected how they interacted in support groups.

Kleinman and Copp describe the fine line researchers walk in managing their feelings about the participants whom they observe and with whom they interact (1993). Although we as field researchers feel the need to maintain some degree of intellectual detachment, we also *want* to feel sympathetic to and connected with our study population. The authors suggest that, like any other interpersonal interaction, field researchers are subject to feeling rules regarding empathy and that we break those rules when we experience any negative feelings towards our study population. We place conditions on the feelings we expect to feel, namely that they must be positive (Kleinman and Copp, 1993). Implicitly, sympathy and intimacy suggest that we understand our research population. Kleinman and Copp emphasize the importance of evaluating all of our emotional reactions, because in transforming feelings of dismay or disappointment, we distort our research perspective and thus our analysis. Rather than dismissing or suppressing feelings of unease, we must reexamine those feelings to refine our understanding of how participants view outsiders, each other, and themselves (Kleinman and Copp, 1993).

Clearly, any potential for my going “native” was nearly impossible given my health and how easily I could have been exposed had I pretended to be ill. Although like most field researchers I wanted to reduce my feelings of “otherness” for the sake of feeling more comfortable and liked, there was no way for me to increase my situational similarity without lying. In essence, I perceived myself as having no avenue to transform my uneasy feelings and noted those feelings in my field notes. Instead I tried to minimize my presence in the group by listening to members and speaking infrequently. Likewise, I caught myself projecting my desire for harmony and inclusion within the group, further heightened by listening to them describe their frustrations with family, friends and health professionals week after week. I recall one particular experience in an emotion-focused group where I felt disappointed with a charismatic male member for being too sexually suggestive with a young breast cancer patient after her reconstructive surgery. However, my negative reaction towards this man led me to realize an implicit but powerful group norm that inhibits most people from offering inappropriate comments.

### Justification for Choosing Cancer Support Groups as a Case Study

According to the most recent statistics from the National Cancer Institute, roughly 8.4 million people current live with a history of cancer. Five-year cancer survival rates have risen to roughly 60% in the 1990s. These improvements in survival are largely the result of major advances in medical technology permitting the early detection, treatment, and management of cancer. The National Cancer Institute recently strengthened its own commitment to issues related to quality of life and survival by tripling its budget for the study of cancer survivorship. Similarly, the American Cancer Society, the nation’s largest not-for-profit cancer research organization, recently announced its move towards investing further in “behavioral and psychosocial issues that affect the lives of cancer patients” (American Cancer Society, press release, 2000). The magnitude of this investment by two of the country's major cancer institutions reflects a larger shift in the medical, political, and social climate regarding cancer (Moyer and Salovey, 1996). Living well, in addition to living longer, has emerged as a top priority within the scientific and care giving communities (Murphy, Morris, and Lange, 1997).

The popular perception of cancer as necessarily fatal does not correspond to the reality whereby cancer survivorship is actually rising. With the appropriate treatment and care, cancer may be managed as any chronic disease such as diabetes might be, permitting individuals' long-term survival and productivity *with* the disease (Murphy, Morris, and Lange, 1997). Importantly, as mortality from cancer continues to decrease, stages of disease progression, treatment, and recovery (or decline) become more prolonged, resulting in extended durations of ambiguity for the patient (Glanz and Lerman, 1992; Dunkel-Schetter, 1982). In other words, the potential to be treated and to live with cancer may continue for protracted periods of time (Dunkel-Schetter and Wortman, 1982). Without the reassurance of a total cure, survivors may endlessly speculate about when and where their cancer may return years into remission. Consequently, cancer exacts not only a physical toll, but also a psychological toll as well.

As cancer patients live longer, there has been a corresponding rise in demand for psychosocial services such as support groups to meet the problems associated with cancer diagnosis, treatment, and survival (Fawzy et al., 1995). Results from the 1992 National Health Interview Study found that only 14% of cancer survivors received counseling and or support services (Hewitt et al., 1999). Of those who did not receive counseling or participate in a support group, the majority stated that they did not need either option; however, almost one out of ten never knew such services existed (Hewitt et al., 1999). Clearly, a small percentage of cancer patients ever seek social support outside their families, peers, or physicians. Nonetheless, for persons with cancer, support groups serve as possibly the most important source of social support second only to family (Muzzin, Anderson, Figueredo, and Gudelis, 1994)

The proliferation of cancer related groups has burgeoned in recent years, in part as a response to limitations of the formal health care system in providing psychosocial care. Beginning in the 1940s and 50s, cancer specific self-help groups initiated by patients emerged, such as the Laryngectomy Association and Reach to Recovery (later subsumed by the American

Cancer Society). The 1970s saw the growth of counseling/therapy groups modeled on the doctor-patient relationship with a professional at the helm (Bloom, 1986). More recent shifts in support groups indicate a shift away from hospital based, counseling groups to more community based education/discussion groups (Bloom, 1986). The hospital setting may only serve to remind members of their illness and evoke negative images associated with their treatment and illness.

Lay or professional leaders may organize cancer support groups, but the more recent trend is to embrace the cancer patient as the leader/expert, despite a professional presence. Their experience translates into expertise that can be shared with the other members of the group. Friends and family members may also accompany those living with cancer; however, the focus is on those living with cancer firsthand. Occasionally, support group members will have both experiential and professional perspectives that may provide an additional dimension to their cancer experience. These members may also serve in a sense as "professional" sources of information and clarification regarding cancer.

On the surface support groups appear to relieve the stress associated with cancer and provide a haven for those who may not feel or appear "normal" in the mainstream world. The problems associated with cancer often dictate the forms that those particular support groups may take. For example, some groups may be organized around a particular side effect such as chemotherapy-induced nausea or lymphedema, painful swelling caused by the removal of lymph nodes. Cancer support groups may address a particular emotional need (laughter groups), advanced forms of disease (metastatic breast cancer), age (individuals in their 20s and 30s), specific type of cancer (brain, gynecological, leukemia) and so on. In their examination of leadership patterns in support groups for the parents of children with cancer, Yoak and Chesler (1985) found that no single type of support group exists even within specific cancer types.

The often unmet need for correct and clear information about the most basic questions or emotional support to "normalize" their feelings and thoughts lead cancer patients without a necessary coping skill to help them adjust (Carlsson et al., 1999). The promotion of positive coping strategies helps individuals normalize their experience in a world where information about cancer seems to be misunderstood or limited (Hermann, Cella and Robinovitch, 1995).

### Data Analysis Procedures

With interpersonal interactions in groups as the unit of analysis, and with my reliance on subjective interpretations, the symbolic interactionist perspective guided my analysis. The data collected in my study and the emergent theory informed one other as the analysis moved forward. I coded and analyzed my field notes with the use of AQUAD, a computer program designed for the analysis of qualitative data (Huber, 1997). AQUAD permits the researcher to systematically code data line by line. First, however, the researcher must theorize which concepts and ideas are important for the study. Coded lines or sections of data may then be linked to these theoretical concepts permitting the researcher to extract and organize data for further analysis.

After a close reading of my field notes, I began my analysis by coding openly with my research questions in mind, moving chronologically through my first set of field notes to my last. In open coding, the researcher reads through a set of field notes line by line to generate insights, connections or topics (Emerson et al., 1995). The research aims to generate as many codes as possible without limiting oneself to preconceived ideas about how categorizations may fit together (Emerson et al., 1995). As I continued coding, I compared each subsequent line or chunk of data to existing codes, either placing it in an existing theoretical category or creating a new code. My data were initially coded for broad concepts such as norms, coping assistance, and ideological beliefs.

The next step after openly coding into broad categories was to begin organizing similarly coded data and to break it down into smaller subcategories of the overarching code or concept. In using AQUAD, I was able to search on a particular code such as “identification with the group” or “negative social support” and save my search as a data file. This enabled me to open the file into a word processing program that allowed me to sort through the lines or chunks of data. Upon further examination certain codes were refined, re-categorized or discarded in an effort to refine the meaning of the concept and clarify its components. Refined coding of a broad concept such as norms resulted in more precise codes that reflected the kinds of norms operating in cancer support groups (emotional, behavioral, and cognitive). Further, in the process of refining my coding, unanticipated key concepts emerged, namely cognitive norms and cognitive deviance. Certain lines or sections of data were multiple-coded depending on their theoretical relevance. Through writing theoretical memos about a particular concept, I captured and elaborated my emergent thoughts and insights regarding the data (Emerson et al., 1995).

I proceeded with my analysis by looking for patterns among concepts by social characteristics. Patterns may be characterized broadly as cross-sectional relationships or sequential processes. A cross-sectional relationship might be exemplified by instances of positive coping assistance that vary by ideology of the support group. The unfolding of helpful or unhelpful coping assistance might reflect a sequential process pattern. In this way, I teased out possible linkages between concepts or themes and wrote memos about the associations that appeared in the data. I attempted to verify the patterns that seemed to be present in my data through counting and cross-classification. These served as means of closely examining the patterns for consistency and clarity. Counting was a way of checking the frequency with which certain concepts appear. Cross-classification checked for further nuances or variations in a particular pattern that may be found across different sets of field notes (Emerson et al., 1995).

In this analysis, I took special care to notate aspects of subcultural phenomena. For example, I relied upon the statements and behavior of participants that demonstrated identification with the group such as beliefs, norms, knowledge, shared jokes, special vocabulary and the like. Conceptualizing support groups as subcultures was the most important concept in this study; however, the research question encompassed the process through which cancer patients joined support groups and how they worked to reduce stigma and emotional deviance. To address these research questions, I searched my data for instances of these two important theoretical categories. In examining the exchange of coping assistance, I coded suggestions made and/or rejected, reactions to suggestions, or stories told about overcoming a problem. All statements made about feeling devalued or stigmatized were coded. Likewise, all statements and/or discussion of feelings and cognitions were coded, especially those referring to how one should or should not feel or think.

In sum, this was an exploratory, qualitative study employing participant observation methods with a small, non-random sample of cancer support groups, selected to maximize theoretical variability by ideology and structure.  This data analysis relied on traditional qualitative methods with an emphasis on inductive analysis.

# CHAPTER III

# THE CONTRIBUTION OF IDEOLOGY TO SUBCULTURE

In chapter one, I contended that cancer support groups contain key elements of subcultures that differentiate them from the mainstream. An element of subculture that remains both distinctive and stable across groups is ideology. The purpose of this chapter is to illustrate the distinct ideological beliefs of cancer support groups that subsequently influence norms and coping assistance given.

Cancer support group ideology arises as a means of mitigating or supplanting inappropriate and incorrect beliefs held by the general public by drawing upon the subjective experience and intuitive understanding of cancer patients. Support group ideology influences the social support process by molding and shaping the specific kinds of assistance one might hope to receive or that fellow group members may offer. As Francis (1997) argues, therapeutic interventions like support groups may be seen as "ideologically driven action" (p. 72) in which ideology serves as guide for of coping assistance, or more specifically, interpersonal emotion and cognitive management. She contends that group ideology helps redefine a situation when individuals' emotions or thoughts fail to conform to what may be expected in a certain situation, or when internal feelings and/or external displays are perceived by the self or others as too intense, too inexpressive, too uncontrolled, or just simply wrong.

Francis (1997) investigated the relationship between participants' emotional and cognitive change and the ideologies offered by professionally run bereavement and divorce support groups. The educational and professional training therapists receive influences the kinds of coping assistance techniques they will offer to those looking for their help. Francis argues that a therapeutic approach to understanding how the world operates constitutes ideology because it "limits the range of frames that can be placed on an event" (p.72, 1997). Professional supporters' definition of the situation reconstructs thinking and feeling norms by invoking the identity appropriate for the situation that subsequently brings sufferers' thoughts and feelings in line with their perspective. In other words, by reframing an event for a support group participant, the facilitator imposes a ready-made explanation for what has occurred in order to facilitate the transformation of deviant feelings or thoughts about the event into positive normative ones. In this way, the facilitator redefines the emotions and the identities of the participants to correspond to the existing group ideology and fosters norms more compatible with his or her professional expertise. Francis's research illustrates an earlier argument made by Hochschild that ideology frames the emotion norms that individuals may violate and require coping assistance to meet (1979).

In Francis's study, professionally run support groups supply a set stock of definitions and work with distressed individuals within a particular therapeutic frame to negotiate a mutually satisfying explanation or definition of the event (divorce and bereavement). Therapists not only supply new meaning, but also prescribe a course of action -- what the individual *should* do (author's emphasis) in terms of how to feel or think (1997b). In contrast to Francis's study, however, some cancer support groups do have professionally trained leaders at the helm who nearly always defer to fellow support group members. It is the members themselves who assist in negotiating a definition of the situation, bringing personal experience and not therapeutic training to the situation. In studying these groups, we may come to understand how fellow suffers come to interpret their own and others' condition from an experiential perspective rather than from a therapeutic perspective.

### Support Group Overview

In order to conceptualize more clearly how ideology may function within a support group, I will provide a brief orientation to how the typical support group operates. I provide greater detail about the function and structure of cancer support groups in the following chapter. Cancer support groups generally follow one of two formats, socio-emotional or informational. The socio-emotional groups, as captured in my research, consist of unstructured peer discussion with minimal intervention by the facilitator, who may be a professional counselor or a fellow cancer patient. Group members direct the nature of the conversation within socio-emotional groups, often flowing freely among a range of topics from the trivial to the serious during the course of a single meeting. At times facilitators join the conversation to prompt quiet members to speak or to elicit more detail from a particularly stressed individual, but they generally remain in the background.

As the name suggests, the primary goal of socio-emotional groups is the provision and receipt of emotional support among a group of people dealing with the same stressor. Group members offer support based on their own experiences to clarify misinformation and misconceptions, to offer empathetic understanding, and to assist with feelings of being helpless, overwhelmed, or ignored. The support offered by socio-emotional groups is not restricted to emotional support exclusively, and, in fact, such groups also offered instrumental and informational support as well. As my data show, socio-emotional and informational support groups frequently overlapped in terms of the type of support each offered, with the major distinction between the two being the dominant *means* of support provision.

The informational groups primarily operate to educate its members about cancer such as understanding one's diagnosis, managing side effects, selecting among treatment options, and caring for one's body. Some have argued that education promotes a sense of mastery and control over illness by increasing knowledge and decreasing uncertainty (Fawzy and Fawzy, 1995; Holland, 1982). Educational groups in my research sample rely on guest speakers, most often health care professionals, to provide professional guidance and advice on a cancer-related topic selected in advance by the group. Discussions often became quite technical in nature as members asked highly specific questions about their particular situations.

Informational groups generally adhered to a more didactic format in which the guest speaker lectured on a topic selected by the group, followed by a question and answer session. By asking questions of the speaker and of each other, members of informational groups shaped the course of discussion that arose. Because informational groups consisted of persons facing similar circumstances, members at times intervened to offer informational, emotional or instrumental aid as they saw fit. In this way, they appeared to supplement the informational aid offered by the guest speaker.

The main ideological beliefs that emerged from my observations of both types of cancer support groups include the importance of following conventional treatment, taking charge of one's treatment, taking care of oneself, shifting one's priorities and perspective, and attending support groups.  I will illustrate how these five ideological tenets shape individual members' own perception of their problem and serve to sustain the groups' existence.

### It Is Important to Follow Conventional Treatment

As will be seen in this next section, many of the ideological beliefs that affirm the collective interests of cancer support groups are explicitly stated by group participants during their exchanges with one another.  However, in the following examples, the ideological principle pertaining to conventional treatment is revealed through the reactions of others to expressed deviance from the groups' expectation.

One of the key ideological principles at work is the belief that fellow cancer patients must adhere to a conventional course of treatment if they hope to beating their own individual cancer.  Perhaps the predominant ideological belief upheld and enforced by the cancer support groups I observed is that conventional cancer treatment provides the safest, surest means of saving or extending one's life.  In other words, if patients want to achieve the best possible outcome this is the only course of action to follow; alternative methods will not be tolerated as a substitution.  Choosing to do nothing or to pursue alternative avenues of treatment in place of conventional treatment in general brings a swift reaction from group members.  All other options are perceived as risky and unrealistic.  In the following example, Victoria senses how the group will react to her trip to Los Angeles where she underwent an alternative healing treatment for mastectomy scar reduction:

> "I know this sounds really wacky, but the next day I could tell a difference in my [breast surgery] scar.  The doctor who does it doesn't make any claims, but he uses it with plastic surgery scars.  Anyway I met a guy from Montreal who had been receiving these treatments twice a week for three months. He was told that he was completely inoperable when he was diagnosed..." says Victoria.
> – socio-emotional group, TN

Victoria signals to the group that she knows taking an alternative medical approach to her cancer will be at odds with the group's strong belief in conventional medicine. At this point, she has discussed an unconventional approach to healing her mastectomy scar that does not necessarily provoke immediate sanctions from fellow members, although she tries to justify her actions by citing a success story of another cancer patient. However, she does get a reaction when she openly debates undergoing chemotherapy:

> "I think of chemo as poison in my body because doesn't it strip the good cells with the bad? I mean how good can that be?" Several people speak at once in defense of chemo and Ann Marie's voice seems win over the rest. "You can't think of it like that or else that's what it will become. Yeah, it takes some of the good with the bad and makes your hair fall out, but that's how you know it working. Hair is made up of fast growing cells and you know the chemo is doing its job when you hair starts to fall out. You have to think of it as a positive," says Ann Marie.
> –socio-emotional group, TN

Without question, Victoria states a belief that the group clearly thinks is wrong. Ann Marie, a health care professional and a breast cancer patient herself, helps her reinterpret the meaning of losing her hair as a positive aspect of chemotherapy in accordance with the group's ideological belief. Patryce also responds to Victoria's comment above, demonstrating how an outsider (in this instance, Patryce's daughter) reframed her perception of chemotherapy, keeping her ideologically in line with the group:

> "Victoria, I have a 24 year old and she was living at home at the time I was diagnosed. I was really questioning the chemotherapy just like (a fellow member) Bob [did]. She said to me, 'Mom, you've got to stop calling it poison. We're not going to use that word around here any more. We're going to call it medicine from now on.' That's what you have to do," says Patryce.
> –socio-emotional group, TN

Thinking of chemotherapy as poison is threatening to fellow members (who have most likely undergone chemotherapy themselves) and believed to be potentially destructive to oneself as the above example indicates, clearly violating a major ideological tenet of the groups. Although the side effects of chemotherapy may *feel* toxic, those same side effects may be perceived as the treatment working, justifying the belief in a conventional approach. Bob recalls his same initial reaction to chemotherapy and the reaction he got:

> Someone in the group indicates how opposed Bob used to be to conventional cancer treatment. “They’ve been nice to you,” he says to Victoria. “You should have seen how they treated *me* when I said I wanted to go the alternative medicine route,” says Bob.
> –socio-emotional group, TN

Bob’s statement shows that the group’s ideological belief in conventional treatment is nothing new, and in fact he too had been judged as out of line. Bob’s experience demonstrates how the group sanctions thinking that is incompatible with group ideology. These reactions to Victoria demonstrate that bringing aberrant thoughts and beliefs back in line with the group’s ideology is an important function of what groups do.

Likewise, in the breast cancer group, Gertrude announces that she refuses to have chemotherapy because she firmly believes her body will be less able to fend off disease. Her comments prompt swift reactions from her fellow group members:

> An older, wiry woman (who’s name I do not catch) on the other side of Gertrude says firmly, but kindly, “Don’t fool yourself about chemo. Chemo is the reason why this whole group of women is alive today.” She makes a sweeping gesture with her arm to the women in front of her. Gertrude replies, “I went in with lung cancer [initially], you know, and my immune system was very weak. I wasn’t going to do anything to make it worse.” Dorothy looks at her seriously with her hands folded in her lap and says, “Well, chemo is not going to destroy your immune system. You’ve just got to do it.”
> –informational group, FL

Dorothy suggests that even the potential complications of chemotherapy cannot outweigh the potential overall benefit of time added to one’s life. For many, the side effects produced by chemotherapy in particular feel worse than having the cancer itself, thanks to the intense nausea and fatigue it induces. The desire not to feel any worse than one already does is understandable and in fact goes against how most people think about illness and medicine. With other commonly experienced ailments, one feels bad from the illness, takes some form of medicine not only to heal but also to eliminate the accompanying aches and pains. Cancer treatment turns this conventional expectation around for many patients, most of whom had no pain from their cancer and felt sick once treatment began. Consequently, patients must be taught to believe that undergoing such rigorous treatment actually helps their cause rather than weakens them:

> "How long did take for you to feel normal again?" asks Victoria. "Let's see, my chemo started a year ago and I think in October I really started to feel myself again." She looks upwards, squinting her eyes in thought. "Yeah, it was October when I started feeling good again." Victoria looks a little defeated. "Listen Victoria, it's going to be hard either way you go -- the conventional route or the alternative medicine route. There's no easy way regardless of what choice you make," says Ann Marie.
> –socio-emotional group, TN

Victoria wants reassurance that if she follows the conventional path that she will get the results she wants. Ann Marie once again helps her understand that while chemotherapy will more likely save her life than any alternative medical route, she must anticipate that chemotherapy has its own challenges. In another example, Diane, the group's facilitator, asks Gerald where he is in the course of his treatment:

> "Well, I am supposed to have two more treatments, but I am not going to do it." "Does the doctor know you don't want to finish your chemotherapy treatment?" asks Diane sounding concerned. "Oh yeah, I told him," he says. "Gerald, you had the flu, too," says Diane. "I had flu-like symptoms, but I know it didn't have anything to do with the flu. I went for my chemo this week and my blood work was really abnormal. I've been having all this chest pain up in here [he points to his chest] and all along here [he points to his side]. It's the same way I felt before I got diagnosed with cancer. The doctor sends me for a CAT scan in two weeks. It doesn't look good. My original cancer was in my colon and in my bladder...I've been dealing with this for a year. But you know what? I'm not doing any more. I've done everything [I was supposed to do] – surgery, radiation, lots of chemotherapy. I want to enjoy the rest of my life and up until now I haven't been able to yet." "Gerald, are you sure the pain is not related to your chemo?" asks Martin. "Yeah I'm sure. This started before I got chemo," says Gerald. "Because when I started to get really bad chest pains with chemo one time it turned out that the area around my heart was inflamed. The doctor told me just to take some Advil to get rid of the inflammation and that was it," says Martin.
> –socio-emotional group, TN

Gerald, tired of the rigors of cancer treatment, wants to quit his chemotherapy without completing the prescribed number of doses because he fears he has relapsed anyway (he found out later that, like Martin, he had inflammation around the heart, not a recurrence). Fellow members work to help him reinterpret what he believes to be a lost cause into a more plausible explanation.  Even when he cites the need for a higher quality of life, no members support his move to quit his chemotherapy sessions.

In the next example, the group facilitator has just informed the group that a former group member died earlier that week from complications of leg cancer.  Although I did not have an opportunity observe this particular person in the group, I understand from group members that her form of cancer would have likely been cured had she followed conventional cancer treatment. She instead subjected herself to a wide range of alternative treatments, including flying to Germany to have her body temperature elevated to a dangerous degree.  Her death brings the following reaction from those who knew and cared about her:

> "You know, I just can't see how anyone thinks that carrot juice will cure cancer," says Jeff in an angry, but highly controlled voice. "I'm with you there, buddy," says Kevin. "I think we're all with you," says Mary Pat looking around at all of us. "She put her body through absolute hell with those treatments.  It's not any easier going that route than it is to have chemo, I'm sorry," says Jeff throwing up his hands. "I mean at least we have studies to show that this stuff works," says Jeff. "Right, there isn't much on the effectiveness of alternative methods, I know," seconds Patryce.
> – socio-emotional group, TN

This group member ignored the group's advice and collective experience to pursue her own belief in unconventional medicine. Her death serves to reify the existing ideology of the group about appropriate beliefs and subsequent behavior.

### It Is Important to Take Charge

A second ideologically important tenet of support groups is that members must take some level of responsibility for themselves and their cancer by gathering information, questioning doctors, and seeking appropriate support all as a means of informing themselves about their cancer.  By educating themselves about the details of their illness, cancer patients may be better equipped to make their own informed decisions about the course of their treatment to ensure the best possible outcome.  Dave, the professional facilitator, articulates the ideology of the group in his exchange with David, a melanoma patient:

> "It was really hard for me to appear totally ignorant, but I really didn't know anything at the beginning. Everything was new, all the terminology and everything. A couple of times, I just agreed with what they were telling me, pretending like I knew what they were talking about when I didn't. I hate feeling like that," says David (patient). Dave, the professional facilitator, says, "You know how a doctor asks you all sorts of questions when he takes your medical history? You have every right to go in there with a list of questions and not let him leave until he has answered them all. I encourage all my patients to get answers from their doctors. That's your time."
> –socio-emotional group, TN

Peter, also a melanoma patient, explains how cancer patients cannot entrust their care completely to their doctors:

> "You expect doctors to know everything and guide you through the process. One doctor knows one thing and not the other, and another doctor knows something else. It was so shocking to find out that you have to be in control of your illness. I've found that the doctor is a tool that you use to help yourself. I hate to think like that, but you have to."
> –socio-emotional group, TN

Peter has reconciled himself to the fact that only he can be his own best advocate, not his doctors. Despite all their training and knowledge, even doctors themselves cannot be relied upon to serve as a definitive source of information.

> "The doctors tell you so little! They ask if you have any questions and you say no. It's so fast you just don't have any time to think of any at the spur of the moment. For example, how do we know if the doctor got all of the cancer? Will [I] have to have chemo later on?" asks Eleanor.
> –socio-emotional group, TN

Ann Marie does not solely rely on her physician's judgment to determine a possible metastasis to another part of her body. She takes matters into her own hands to determine for herself whether her symptoms could possibly be something more serious:

> "One of the things she's (Ann Marie) most worried about is whether or not the cancer originated in the breast. I guess breast cancer rarely goes to the lower back the way hers has and she's worried she might actually have ovarian cancer. You know ovarian cancer has very few symptoms and lower back pain is one of them. She's read everything. You

> can tell she's a nurse, can't you? She even called to get the doctor's dictation from the surgery read to her over the phone," says Ed. "That is very Ann Marie, but I would do the same thing," says Fern,
> –socio-emotional group, TN

Taken together, these statements suggest cancer patients cannot afford to be passive actors in their own care because even doctors with all of their medical training and experience are not an infallible medical resource for patients. From a more mainstream stance, cancer patients' skeptical approach to their own care may seem cynical and even foolhardy. Nonetheless, cancer patients believe they have a responsibility to take charge of their doctors if they are to receive the highest standard of medical care.

Thus, the ideology of cancer support groups dictates that patients must avail themselves of all possible sources of information pertaining to their particular situation, whether about the latest medical advances or about whom to consult. Perhaps by encouraging each other to take a more proactive stance, they feel they are afforded some level of control over their illness and its progression. Furthermore, patients' desire to remain in charge of their illness through their own research and understanding better equips them to challenge the medical decisions handed down by their doctors and to draw their own conclusions. The following example illustrates cancer patients' resistance to being at the mercy of the medical establishment in making decisions *for* them rather than *with* them:

> "I told my doctor, any kind of medical terminology you want to use, you just go ahead. I'll get a copy of my records and figure it all out myself. I've already been to the American Cancer Society and got a stack of stuff this high (Agnes holds her hand about a foot off the couch). I've done all the research and I know all the things that can happen. What else do I need to know?" says Agnes.
> –socio-emotional group, TN

Agnes refuses to defer to her physician or be intimidated by his used of medical jargon. Similarly in the following exchange, the group turns to the subject of Dr. Cohen, a local oncologist, whom two other members see currently. Patricia went to see the same doctor, but only saw him once. She did not tolerate being treated disrespectfully:

> "I told him directly, 'I don't know if you're having a bad day or what, but I don't feel very comfortable with having you as my doctor.'" "Wow, Patricia, I'm impressed. That's strong of you. People are usually never that direct with their doctors," says Sarah, the professional facilitator.
> –socio-emotional group, TN

Being a physician does not automatically confer a level of deference or respect usually afforded someone with that kind of professional background. Interestingly, tonight’s night’s guest speaker, Dr. Bates, defers to the men in this prostate support group:

> "I'm a doctor, a surgeon, which means that I'm not the smartest man in the room. There are lots of opinions about when to treat or not to treat after a rise in the PSA and how long you'll live. It’s decades, you'll be happy to know. I looked on the Internet because patients brought it to my attention and there's web page where you enter in your PSA. It gives you information about whether your cancer is local[ized], metastatic or whatever.”
> –informational group, TN

Even Dr. Bates seems to suggest that cancer patients deserve the respect usually afforded to professional colleagues or at least active collaborators. Another guest physician speaker in the prostate group echoes the opinion of the physician above:

> “No matter what, patient opinion is the most important and some prefer observation. It doesn't matter what the doctor wants because he will go with the patient's preference [for treating his cancer].”
> – informational group, TN

The latter doctor seems to be suggesting that deferring to the wishes of the patient should take precedence over the medical opinion of the doctor. In this manner, these two doctors work to reinforce the ideology of cancer support groups. Tonight’s prostate cancer support group speaker fields questions posed by the group and responds below to a question about the role of alpha blockers and bladder function:

> “Alpha blockers open the neck of the bladder, but [vaso-constrictors] like sinus drugs actually tighten the bladder. The medicine [alpha blockers] loosen the muscle tone. It's given to women for incontinence, but it raises blood pressure at the same time." The

> doctor pauses for a moment, looks around and says," You guys are asking some great questions tonight. I'm really impressed.”
> –informational group, TN

The doctor actually makes a couple of additional remarks during the meeting about the quality of the questions. His observation appears to speak to the fact that as evidenced by their questions, these men seem to be really well informed about their disease and its related effects.

Conversely, Margaret’s defensive comment also serves as a self-acknowledged violation that highlights the “take charge” ideological principle at work:

> After a highly technical discussion of a new breast cancer surgical technique, Margaret says, “I guess I am just too stupid. I just went blindly into chemo. I didn’t even know about any of this stuff. I just trusted the doctor to do what’s right. I mean he’s been to medical school and I haven’t.”
> –socio-emotional group, TN

Margaret did exactly what cancer support groups believe patients should never do: unquestioningly accept the physician’s judgment. Sam simply did not know any better when she was first diagnosed, but she knows better now:

> “Ann Marie, you totally impressed me when I met you. You came in here and you had done all this research about your cancer. When I was diagnosed, I just let the doctors make all the decisions. I didn’t do anything.”
> –socio-emotional group, TN

The previous comments largely illustrate how cancer patients should resist acquiescence when determining their treatment.

Taking charge of oneself has its advantages, mainly that one will be more apt to live longer. Reference to the group ideology is implicit in Caroline’s excitement in having outlived doctors’ initial prognosis for her:

> “My husband and I went up Mayo where they cut out as much as they could and then told me that I had at most three years to live. My husband has been by my side for everything. What would you call us, Becky?” asks Caroline. “Joined at the hip?” offers Becky. “No, I

> mean another word for being super aggressive [she laughs]. We refused to accept [their] diagnosis and look, I am here six years later.”
> –socio-emotional group, FL

Internalizing the group ideology worked favorably for Caroline. This kind of success story helps maintain and reinforce group members’ belief in this ideological tenet. Perhaps having been aggressive with her doctors after her diagnosis, Caroline believes that had she recognized her own symptoms earlier she might have altered her fate:

> “Breast cancer is no longer the death sentence it used to be. You hear to lots of women who get it and survive. Ovarian cancer is talked about much less frequently, even though it's more deadly. Most women don't know they have it until it's too late. Look at me. I didn't go and get checked out until I was all bloated and sticking out to here." [Caroline gestures with her hand to imitate a distended abdomen.]
> – socio-emotional group, TN

Going a step further, Caroline applies the thinking of the group to her own hairdresser whom she feels is not being aggressive enough in being screened for ovarian cancer, although the hairdresser has no family history of the disease:

> "Even my hairdresser didn't believe that a pap smear wouldn't pick up ovarian cancer. I mean she knows me! I've been going there for ten years or at least while I had hair. I told her that you have to know to ask for the tests that the card tells you about. She still said to me, [Caroline uses a dippy voice] 'Well, my doctor told me that a pap smear is enough, but I guess I'll ask him again.' For crying out loud, I have the cancer, I know!"
> –socio-emotional group, FL

Caroline takes for granted that ovarian cancer is a relatively infrequently occurring cancer in women. Thus women who should get screened are usually only those with a strong family history (usually a first degree relative) of the disease. She applied the ideology of the group to someone outside the group and discovered that her hairdresser, like most outsiders, did not share Carol’s same sense of urgency.

### It Is Important to Maintain a Positive Outlook

One means of attracting and retaining members is the promotion of an optimistic outlook regarding one's cancer and one's future. The support groups urge members to focus on the positive and encourage the belief that one will outlive one's cancer. Having a positive attitude also suggests that one will keep up a fighting spirit and not let cancer beat them, as seen with Caroline:

> James says, "Dr. Jones told us to reemphasize this with this group. When Caroline first got cancer, her doctor gave her two weeks. Jones came along and told her it's her attitude. Now she's in her seventh year and the doctor at Mayo says she's too feisty [to die]. Dr. Jones wanted us to reaffirm that attitude makes a BIG difference. In Korea during the Korean war they had a study of these American prisoners who were captured by the Koreans and over half of them who died in captivity died of "give up-itis". They had no physical ailments. They just pulled a blanket over their head and they died....It's the attitude that if you want to fight cancer, you must have a good attitude [sic]....There's no question in my mind that if she had listened to that doctor and done on a cruise [she would have died]. She said to the doctor, 'If I were your mother, what cancer center would you want me to go to?' He said, 'I would tell you to get your papers in order." "So you thought you were going to die?" clarifies Eddie. "Oh yeah. She sees him every now and then and says, 'I'm still here!'"
> – socio-emotional group, FL

In a subsequent meeting Paulette holds Caroline up as a model of success to the rest of the group:

> Becky says she has not heard anything [about Caroline's absence today]. "Isn't Caroline a great role model?" says Paulette looking around at all of us. "She has been through so much and she's still here. She was supposed to be dead six years ago! She's just terrific." [We learn later that Caroline had a doctor's appointment in New Smyrna Beach that prevented her from being at the meeting today.]
> – socio-emotional group, TN

Caroline has outlived her doctors' prognosis for her cancer and thus deserves to be emulated as someone who has exceeded all others' expectations for her survival. The example Caroline sets is crucial for underscoring the possibility that others too may outlive their own prognoses since no one truly knows how long any cancer patient will actually live, not even the experts. Jack seems inspired knowing that there are other survivors of his same cancer who have attended in the past:

> "Believe it or not, we used to have a guy, Monty, who used to sit right here in our group who also had carcinoma," says Diane. "I was completely shocked when Fern [the director] told me that five members here had carcinoma. I've been told that of all the cancers, carcinoma's a good one to have," says Jack.
> – socio-emotional group, TN

Robert shares the good news about his cancer levels falling considerably:

> "I graduate tomorrow – at least they call it graduation anyway. I just got [the results of my prostate cancer screening test] and after two months on the hormones, my PSA went down 90%. For forty days in a row I have been [at the doctor's office] for my treatment, followed by 38 days of radiation," says Robert.
> – socio-emotional group, FL

Robert's spirits seems to be buoyed by his good news, although he will continue to be followed over the upcoming months for any rise in his cancer marker. All improvements deserve to be recognized as Belinda demonstrates below:

> "I'm just focusing on the positive right now, you know? I know this is gross, but I had a normal b.m. for the first time in a long time. My doctor said that since I stopped chemo eight weeks ago that my tumor hasn't grown. As far as I'm concerned that is good news," says Belinda looking around the room for validation. "That is good news," affirms Jeanne.
> – socio-emotional group, TN

Despite being in hospice care right now, Belinda tries to maintain a positive outlook on her own situation by being thankful that her situation at least for the time being is not worsening.

As discussed in chapter one, cancer perhaps more than any other disease conjures up images of certain physical debilitation and protracted death. Interestingly, as the exchanges below will illustrate, cancer patients appear keenly aware that their own respective situations could always be much worse and give thanks for the health they have. For example, Gabe has a serious form of cancer in which his bones can break while performing routine, everyday tasks.

Where healthy others might find being in his situation dismal, he feels thankful that he can still engage in the activities he enjoys:

> “I try to keep active. Unfortunately, that's where the pain comes from and again, going back to this hematologist, he started giving me a few years ago a drug called Palmitromate that helps the bones....Otherwise, I couldn't play tennis and would be heartbroken. I also feel being active and playing tennis has helped me tremendously and I count my blessings every morning. Like a friend says, if you can get out of bed and walk around, count your blessings and I do.”
> –socio-emotional group, FL

Having physical mobility is certainly something for which to be grateful, according to Gabe. But also, if nothing else, just having some amount of life left to live is reason enough to be thankful:

> "There are definitely worse things you can have than cancer. We just had a 40 year old woman at work die of a blood clot during childbirth. She was 40!" says Ann Marie
> – socio-emotional group, TN

> “I feel lucky to have cancer in some ways. I mean I’m still alive!” exclaims Nanette.
> – socio-emotional group, TN

Because oftentimes their situations can be worse, cancer support groups members often find themselves taking stock of their lives and appreciating what they have. In this way, cancer support groups’ ideology reflects the acquisition of a new positive perspective gained from the experience of having cancer. In the following exchange, Kate and Dave discuss the importance for all persons to live in the moment:

> "We just read a book in which they recommend having a treat day once a month. This woman treated herself to a new outfit every time she completed a treatment and managed to replace her whole wardrobe," says Kate. Dave talks about the importance of living your life normally and not constantly denying yourself. He tells the story of a patient of his who always wanted to wake up and have breakfast on the table, but never did. Apparently, he expressed his desire to his wife who dismissed his request. "All of the sudden he gets cancer and his wife finally makes him the breakfast he always wanted.

> But why does it take cancer for you to do the things that you always wanted to do?" Dave asks. "If you want to do something, you should do it."
> – socio-emotional group, FL

The perspective gained from cancer puts all other aspects of members' lives in perspective, too. In handling his small dog's vomit, Jeff realizes that cancer has increased his tolerance for the previously intolerable:

> "Cancer is just a wake up call to notice the rest of your life," says Keith. "It's like people say you're either living life or you're enjoying life. Your perspective changes. I know mine has. Remember when I was talking about throwing up and my father and how I just couldn't take it at all? My little dog started heaving and I caught his throw-up in my hands. Can you believe it? I caught it my hands and just went to the sink and washed it off. I don't know what he ate, but he threw up a gallon all over the bed, all over the newly washed sheets. What a mess! Cancer is just part of the journey of life," says Jeff.
> –socio-emotional group, FL

Cancer may also been seen as an extreme means of acquiring empathetic understanding for others:

> "Do any of you feel like this a test as Dale was talking about?" asks Diane. "A test? What do you mean by test?" asks Agnes. "Umm, I think I mean being tested spiritually," says Diane. "I'd rather not think of it has a test. At test makes it sound like some people pass and some people fail. I think of it as a lesson. We all have lessons to learn and for some of us, it takes a bigger thump on the head than others. Sometimes you have to learn to walk in the shoes of others just like Dale had to," says Agnes. "Like Job in the Bible," adds Dale.
> –socio-emotional group, TN

Because cancer patients usually acquire a keen awareness of their own mortality, they cannot afford to take life for granted:

> "You really learn to appreciate even the smallest things," says Anne. "Did anyone notice the moon this week? It's has been just amazing and normally not something I would have paid attention to," says Bianca.
> –socio-emotional group, TN

Dale has been seriously debilitated by his brain tumor and subsequent stroke, making his movement and speech extremely difficult. Even though he is by most standards in the worst condition of all the support group participants I observed, he still remains thankful to be alive at all:

> "I can't go running like I used to. I used to ride my motorbike and I can't do that anymore. I used to go on the radio and obviously I can't do that. I can't sit around and feel sad for myself. There are lots of things I can still do. I have had so many near misses in my life that I am lucky to be here at all."
> –socio-emotional group, TN

Where healthy others might find David's situation a depressing and perhaps an intolerable way to live life, David's gratitude to have any life left to live demonstrates a shift in perspective. The uncertainty associated with cancer weighs heavily on members's minds. Members worry that their situations could take an unexpected turn for the worse. However, the ideological belief in keeping up an optimistic outlook works to dismiss such fears as irrational or over reactive. Changes in perspective or priorities brought about by cancer help to keep positive attitudes going in the group. Maintaining the momentum of optimism keeps members' spirits up, thereby enhancing the likelihood of members returning week after week or month after month.

### It Is Important to Listen to Your Body

Explicit in the comments made by support group participants is the belief that cancer patients are obligated to listen to their bodies in order to take care of themselves. These quotes suggest that cancer patients urge each other to take care of their minds and bodies as they would when recovering from any kind of stressful experience. By taking care of themselves, they attempt to leverage some control over their situations, preventing them from worsening. In the following instance, members appear to be referring to an unspoken belief that one's life should slow down in order to heal:

> "Several of us are several months out and the reason we're doing so well is because we took care of ourselves. You have got to take the time to rest," says Bob. "You have to remember that you won't always be like this and that you will get better. You have got to

> do it to regain your health. Otherwise what is the alternative? Death?" Jeff seems to laughs at his death comment, but he is trying to convey an important point. "I know that sounds terrible, but it's so worth it. There were days where I only got up out of my chair twice to pee and that was it. You'll get back to your normal self. You really will," he adds. "Right now, you've got to stop and listen to your body and know that it knows what's best for itself," says Bob. "You've got to just veg out if you want to regain your strength," adds Keith.
> –socio-emotional group, TN

Resting appears to be an essential element of recovery, although certain members try to resist the need to do so, as in Ann Marie's case:

> "I kept working too, but it was too much. For certain procedures I could sit down and that was okay. I work around all these medical people who keep saying, 'You can do it. Hang in there. Be strong.' I mean I know what they're trying to do. They want me to persevere and fight it, but I just couldn't. I just had to take a rest. My body was crying out for a rest that I wasn't giving it. You need to give yourself a break and give in. It's only temporary," says Ann Marie.
> –socio-emotional group, TN

Perhaps in understanding that members will not always have to nap or rest for the rest of their lives, they will grant themselves permission to do so while undergoing treatment. Pasty wants to continue her exercise regimen even though she recently underwent a mastectomy and is currently undergoing chemotherapy:

> "How's the other side [of the breast] doing?" asks Ann Marie. "Perfect. It healed perfectly. No problems," says Patsy. "How big was your tumor?" asks Jeanne. "About .75 centimeters," replies Patsy. "And you had both breasts removed?" Pam asks incredulously. "What about walking?" suggests Kevin. "You could walk and at least not move your upper body any more than you have to." "Honestly, Patsy, you probably shouldn't be doing anything right now. You're in your what, second round of chemo out of how many?" Ann Marie asks. "I will have had a total of six rounds of chemo when I'm done," says Patsy. "Yeah, you have got to take it easy and not push so much," says Ann Marie. "Even well-trained athletes have to take time off to let their bodies rest," adds Kevin.
> –socio-emotional group, TN

In essence, Kevin shows Patsy that cancer in some ways is an endurance event and like any athlete, the rest only enhances their ability to compete. Moreover, in discussing the failure of Patsy's mastectomy incision to heal properly, she reveals she has been swimming three times a week:

> Several people all speak at once to voice their concern about her continuing to get her wound wet. "Well, no wonder you're not healing!" says Ann Marie who happens to be a nurse. "The surgery you had was a particularly vascular surgery. It's complicated to do and you're in surgery a long time." I see Sam and Judith nodding in agreement. "You had the trans- [something] flap to remove your breast, right? "Yeah," says Patsy sheepishly. "With that surgery you shouldn't be doing any upper body movement whatsoever. You have got to rest and let that wound heal," says Ann Marie. "No swimming?!' Patsy shakes her head in disagreement.
> –socio-emotional group, TN

Still she tries justify her need to handle her stress through exercise, arguing that she cannot afford slow down with work either:

> "I am the sole breadwinner for me and my daughter. I have to keep working. I have used up all my sick leave and almost all my vacation. My boss, she's so great, that's why she's trying to get me working again because she knows that I want to save my vacation time for a real vacation next summer," says Patsy. "I didn't go back to work for a year and I lost my job," says Jeff with a laugh. "I kept working, but during the second round of chemo, I had to take off. Still after this much time, sometimes it just hits me and I have to say, 'Hey, guys give me twenty.' And I go sit my office and close my eyes for twenty minutes," says Kevin. "I had those days where I slept 18 hours at a stretch during chemo. You can't help it. You have to rest your body," says Sam.
> –socio-emotional group, TN

Group members remain steadfast despite Patsy's excuses. Cancer support group ideology seems to dictate that by resting one's body and restricting activities, one will eventually return to a more normal level (e.g., pre-cancer) of activity.

In the following exchanges, cancer patients appear to reference an implicit group belief they should be eating better to improve their health and maintain their strength. Peter talks about the food on a recent vacation:

> "We took a trip into Amish country by myself while we were in Philadelphia. Oh, I had a wonderful time driving around!" Peter exclaims. "We were driving around that area when I saw a sign for a smorgasbord. It was $25 a person, which isn't so bad for all you can eat. I couldn't stop thinking about all the food that would be there....I stayed away from the desserts and the meat, but I ate everything else."
> –socio-emotional group, FL

Peter suggests that perhaps had he not had cancer, he might have indulged himself in consuming more fatty foods. He allowed himself to enjoy the smorgasbord anyway, though he stuck to his diet. Trying to eat healthfully and not "feed" the cancer further takes an incredible amount of willpower:

> Currently, Peter takes 65 vitamins a day, as Kate nods her head. Obviously the heavy vitamin regimen is familiar to them too. "We follow the no sugar, no fat diet," says Peter. Kate says that they also follow the same diet. "We're basically vegetarians at this point. We've done the juices, the vitamins, the teas, all that stuff. But now we're out of that routine. It takes a lot of energy to follow that routine." "When he's out of town I get together with my girlfriends to drink beer, eat pizza and cookies, you know you go a little nuts. I mean we follow such a strict diet, it's hard," says Betsy, Peter's girlfriend. "I've had so much carrot juice that I am turning orange from the beta-carotene," says Peter holding up two bright orange palms.
> –socio-emotional group, FL

Maintaining that sort of willpower takes a tremendous amount of effort every day. Below, Keith tries to justify Patryce's occasional eating binge, thereby violating the ideological principle at work:

> "Krispy Kreme!" exclaims Patryce. "How many have you had today?" asks Sam. Patryce looks down at her feet and says in a low voice, "I've had six today and yesterday! Oh my god, I went on vacation with my brother to my hometown of Savannah and I insisted that we stop at the Krispy Kreme. I ate one and immediately I made him pull over and I threw up. I just got so sick. Now I don't have any problem eating whatever I want. I went to church yesterday purposely for the catered lunch they were going to have afterwards. I mean I had to plan it so I would be awake long enough to eat. And they had Corky's barbeque!" says Patryce. [Everyone groans at the thought of it.] "I ate three desserts, I had two platefuls and took a plate home with me," she adds. "Well, putting on ten pounds isn't going to make a difference in the long run," says Jeanne. "I've actually lost a little weight to tell you the truth. I don't know what my problem is," says Patryce. "I mean as long as you are eating all the healthy stuff, you're probably balancing it all out

> anyway," Jeff says. "You need to listen to your body. If you are craving that stuff, that's your body's way of telling you that you need it," says Keith.
> –socio-emotional group, TN

Although Keith tries to rationalize eating indulgence in terms of fulfilling a physical need, most support group members recognize their unhealthy cravings as a violation:

> "When I was going through chemo, I started craving carbohydrates. I had to have mashed potatoes," Anne shrugs her shoulders. "I never have been a big fan of potatoes in the past and then I had to have them." "I've been eating a lots of sweets lately. Right now, it's pumpkin pie, ummmm," Jeff says opening his eyes wide. "Oh, I know and blackberries, oh..." Patty's voice trails off. "You know for years I avoided things like bacon and peanut butter. When my sister comes to town she brings peanut butter, but she usually takes it home with her. I had three peanut butter and jelly sandwiches today with the peanut butter and the jelly slapped on there so thick [pretends like he's holding a gigantic sandwich] that a big glob of jelly dropped onto my plate. Ummmm."
> –socio-emotional group, TN

Taken together, the comments about resting and eating well suggest that cancer support group members are aware of a need to care for their bodies as best they can.

### Support Groups Offer Safe Haven From the Outside World

When cancer patients expressed their appreciation for their support group, they referred to their gratitude for information, emotional support and validation; however, these comments also reflect yet another ideological principle at work – that support groups provide safe haven from the outside world. Improvements made in one's mental health through sharing experiences, empathetic understanding, and gaining information all serve to sustain support groups and maintain membership. Although Victoria may be undergoing treatment to benefit her physical health according to Bob, support groups conceivably benefit her mental health by allowing her to express herself freely:

> "I know the cancer is in my breast, but I think that's just a symptom of something more systemic going on in my body and so I want to treat my whole body," reasons Victoria. "This group is the best thing for you. I don't know what other people do. They must just crawl the walls. I don't know where I'd be without this group," says Bob.

> –socio-emotional group, TN

Her “whole body” clearly includes her emotional well-being, an aspect of cancer care often left unaddressed by the medical establishment. Support groups also serve as an especially helpful source of information, validation and reassurance for strange or unusual symptoms that members might experience:

> "That's the great thing about this group – you get all these strange aches and pains and you think that every little thing could be life threatening. You come to this group and ask, 'Hey, is it normal for my arm to ache like this?” [She holds up her arm and squeezes it with her other hand.] Someone says, 'Yeah, I get that too.' Then other people second and third the way you are feeling. You can't rely on the doctor to answer every little question you have."
> –socio-emotional group, FL

As demonstrated in the section addressing taking charge of onself, doctors often come up painfully short in the care of their patients. Support groups try to compensate for the deficiencies of others, but as these comments indicate, often the best support comes from similar others:

> "I don't know where I'd be without a support group," says Bob shaking his head.
> – socio-emotional group, FL
>
> "You just feel so much better being around other people who've gone through it. I think it would be scarier to sit at home by yourself because left alone you always think the worst," says Mary Pat, laughing.
> –socio-emotional group, TN
>
> "My wife and I having been dealing with this ourselves. We finally realized that we were at the end of our lines [sic] and that we really needed some outside support, so we came to this place," says Jack nodding. "Well, you came to the right place," says Martin high-fiving Jack. "It's an incredible place," says Agnes knitting.
> –socio-emotional group, TN

Having empathetic understanding helps members feel more comfortable expressing their concerns without the fear of being misunderstood or criticized:

> “....This group is so amazing. I have never been in anything like it before, of course this is the first support group I've ever been a part of. Here we come in and reveal our deepest insecurities and worries to one another. The level of intimacy is just amazing to me. We're allowing people to really see us." "This is a place where you can lower your guard," says Keith. "You gain a whole new perspective being around one another. It's hard to articulate to other people," says Ann Marie. Sarah, the professional facilitator turns to me, "Isn't this group amazing?”
> –socio-emotional group, TN

However, not just any support group can offer its members the empathetic understanding they need. Members need to perceive situational or experiential similarity along some dimension in order for groups to work best for them:

> Kate, the wife of a melanoma patient, turns to Dave, the professional facilitator, and says "We're so glad you're offering a support group just for melanoma. We've gone to general support groups, but for the most part the people there are so much older than we are. We can't really relate to people in their sixties and seventies. They just don't have the same kinds of issues we have like raising small children. We really need this."
> –socio-emotional group, FL

Kate and her husband have found the right cancer support group “fit” for them, one that specifically addresses melanoma and other issues people in their thirties have. Conversely, Agnes who has breast cancer chooses to avoid breast cancer specific support groups. She explains:

> "I don't think I need to hear any horror stories. I just find being in a group of people with all different kinds of cancer much more helpful. Even though Gerald has a different cancer from me, I'm sure I can learn something from his experience as well as you and you." She looks at each of us. "I went to the morning group and they just didn't have much to offer me. I thought this group would be the right fit for me."
> –socio-emotional group, TN

Although the reasons may differ, both quotes illustrate that cancer support groups work for different reasons among different members. As the exchange below demonstrates, members have a difficult time when others disagree with them about the benefits of support groups:

> "I understand that we had another new member as well," Diane, the professional facilitator) continues. "Tony" offers Martin. "I wonder if he's a running a little late tonight,"wonders Diane aloud. "I don't think he's coming back. I could tell right off last week that dude was in denial. I thought about him all week long. I saw him go out for a breather and I decided to go out for a breather, too. I told him, 'Look, please don't turn your back on this place. Give it another chance.' He just looked off in the other direction," says Agnes. "Well that happens sometimes. We have had people come here one time and decide it's just not for them. Often they'll come back a few months later," says Diane. "I noticed it, too," says Gerald, "I tried to connect with him after the meeting, you know, go and get some coffee or something." Gerald just shakes his head and says, "Nah, he wouldn't have any of it."
> –socio-emotional group, TN

Both Gerald and Agnes pleaded with Tony to return to the group, reinforcing the belief that groups have much to offer their members. His rejection of the group almost appears to be a personal affront to both members, underscoring the importance of this belief to its subscribers. Regardless of the reason, cancer support group members believe that groups are beneficial as evidenced by their positive statements and exchanges with one another. Moreover, this ideological belief is clearly sustained over time by the consistent attendance of the participants in weekly or monthly meetings.

### Conclusions

As evidenced by the statements made in this chapter, support group ideology either explicitly or implicitly shapes the beliefs of the members and consequently the interactions they have with one another. These ideological beliefs include believing in conventional medicine, taking charge of one's treatments, keeping an optimistic outlook, listening to one's body, and finding safe haven. Support groups generate their own appropriate beliefs that serve to counteract inaccurate perceptions held by the mainstream.

Certain ideological beliefs appear fairly conventional on the surface, such as the importance of following conventional medicine or listening to one's body, and seem to reflect popular thinking. However, important aspects of these beliefs clearly do contradict publicallyheld beliefs or at least temper those beliefs somewhat. For example, following the treatment course prescribed by one’s doctor seems fairly standard, but challenging the doctor’s professional opinion about which course of treatment to follow is not. The public believes it is crucial that one keeps up a fighting spirit and positive attitude, but when meeting this goal starts be become overwhelming, the support group ideology says members need to give themselves a break.

Wuthnow (1994) argues that Americans characterize themselves as “rugged individualists and loners”(p.191) who prize their privacy and time alone. At the same time, he argues that these are the very same people who find themselves attending support groups to meet their individual needs (Wuthnow, 1994). Coping with cancer, in particular, is too hard without the help of a support group, according to the ideology. Cancer support groups offer a distinct outlook on cancer that incorporates both conventional and unconventional thinking that contributes to the subcultural nature of cancer support groups.

The mixing of mainstream and subcultural beliefs in cancer support groups also promotes a specific approach in how groups think one can recover best from cancer. They also function to keep members satisfied and involved over time. In the next chapter, I will examine the norms at work in cancer support groups that shape the structure of the group as well as the thoughts, emotions and behaviors of the members. Ideology has important consequences for behaviors, emotions, and cognitions because it helps frame how one views one’s illness and guide the advice given to members. Chapter five will demonstrate how ideological beliefs get translated into coping advice.

# CHAPTER IV

## PROCEDURAL, EMOTIONAL, COGNITIVE, AND BEHAVIORAL NORMS IN CANCER SUPPORT GROUPS

On numerous occasions sociologists have documented the existence of norms that regulate behavior in all aspects of society. Hochschild (1979) first suggested the existence of “feeling rules” that govern emotional exchanges in given situations; similarly Zerubavel (1997) pointed out that differences in thought may be also socially differentiated (the discussion of which I will return to later). Feeling rules or emotion norms implicitly delineate a range of suitable private feelings for specific situations, learned through social exchanges. Feeling rules also include guidelines for the duration and intensity “of what it is fitting to feel” (p. 563). Consequently, the realization that one may be out of step with social convention serves as a reminder that a person has violated a norm for a particular situation (Hochschild, 1979). Expression norms, on the other hand, guide how one should appropriately display one’s feelings outwardly, including towards whom, how strongly, and for how long.

Violations of these norms constitute emotional deviance: “experiences or displays of affect that differ in quality or degree from what is expected in given situations” (Thoits, 1990). An instance of emotional deviance occurs when “an individual reports that his/her feelings or expressive behaviors differed from what he/she thought was expected in a situation” (Thoits, 1990). Fellow group members may be motivated to address emotional deviance through confirmation of non-normative feelings or displays (by conventional standards) and legitimize those feelings, or they may negatively sanction the emotion in accordance with their own normative requirements.

Zerubavel (1997) argues that what and how we think reflects our membership in particular “thought communities” or social groupings, demonstrating that thought, too, is grounded in social experiences. Cognitive norms reflect how members within a certain thought community adapt their thinking to conform with specific group beliefs. Cognitive differences demonstrate the ways different groups come to constrain what we think, invariably resulting in “cognitive deviance.” At times, members expressed thoughts or beliefs that appeared be inappropriate or incorrect both in terms of the larger society and within the cancer support groups themselves. Cognitive deviance mirrors emotional deviance in that thoughts and beliefs, like feelings and emotional displays, will be subject to negative sanction from the group if they violate group ideology.

Following Thoits's elaboration of self-labeling processes, a person first defines herself as deviant when her emotional reaction does not match the governing emotion norm for that situation (1985). Awareness of emotional deviance may arise either through the imagined reactions of others – leading to self-labeling – or through the acceptance of others' labeling (Thoits, 1985). Central to the understanding of the self-labeling processes suggested by Thoits is the ability of persons to take the role of the other vicariously (1985). One does not require the actual actions of others to know how they may respond to or think about one's intended or actual feelings, thoughts and actions. Self-labeling theory assumes that individuals are well socialized enough to know the normative expectations for appropriate behavior, thoughts and emotions in certain situations and to recognize violations (Thoits, 1985).

The experience of cancer poses a particular problem for those in search of normative guidance for their feelings, thoughts and behaviors. Very often the understanding of what one should expect to feel, how one should express oneself, or how one should think when one has cancer seems to be missing in mainstream society, despite the frequency with which cancer arises in the general population. Overall, the norms perpetuated by American culture for those experiencing adverse life events often appear mismatched with regard to people's actual experiences. Receiving a diagnosis of having a potentially life threatening disease often represents an both an unexpected and non-normative transition into an unfamiliar and threatening situation. Self-reports of emotional deviance or cognitive deviance may be more apt to arise in the absence of normative guidance (Thoits, 1990).

As mentioned in the previous chapter, cancer support group ideology arises as a means of supplanting deleterious, even if correct beliefs held by the general public by drawing upon the subjective experience and intuitive understanding of cancer patients. Support group ideology may affect the social support process by affecting the potential range of social support and coping assistance one might hope to receive in that particular format. As Francis (1997) argues, therapeutic interventions like support groups may be seen as "ideologically driven action" (p.

72) in which ideology serves as a form of coping assistance, or more specifically, interpersonal emotion management. She contends that ideology helps to redefine a situation when emotions, thoughts or behaviors fail to conform to what may be expected in it. Internal feelings, thoughts and/or external emotional displays and behavior may be perceived by the self or others as too intense, too inexpressive, too uncontrolled, or just simply wrong.

This chapter will document four different kinds of norms that uphold the ideological principles at work in cancer support groups. First, I will outline the procedural norms that structure the functioning of the groups themselves. Procedural norms consist of a set of group-related behavioral norms that shape group process. Next, I will discuss the emotional, behavioral and cognitive norms that instruct members how to feel, act and think with regard to each of the five ideological beliefs described in the earlier chapter. Where possible I will also show that members are aware of mainstream norms and their attempt to meet them or supplant them with the norms that govern the group, given the circumstances. In this manner, cancer support group members may be motivated to manage or alter their emotions, behaviors and thoughts so as not to incur norm violations both in and out of the group. By illuminating the norms at work inside support groups, I aim to illustrate the rules that uphold group ideology, and in the following chapter, the coping assistance strategies that are used comply with norms and ideology.

### Procedural Norms

Procedural norms are the implicit but socially shared guidelines that govern the structure and functioning of cancer support groups. With the exception of the prostate cancer support group, all groups kept track of members’ attendance, always noting member absences within the group at the outset of the group. Generally, participants would rely on the facilitator or fellow group members to relay the reason for their absence. Members worried when no excuse was given to explain the absence of a fellow member. Arguably, the worry over someone’s absence reflected a deeper fear that perhaps something serious had happened or, worse, someone had died unexpectedly.

In the following example, the professional facilitator and members inform each other as to absent members' whereabouts:

> Mary Pat, Patryce and Karen enter the room. Each of them expresses her pleasure at seeing Bob in the group tonight. "Fred said he'd try and make it tonight," says Keith to Sarah. "Oh, he's thinking of coming at all?" says Sarah sounding surprised. "He said he'd try anyway," says Keith with a laugh. "Also, Sam called and said she wouldn't be here tonight. She's got a sinus infection. She asked us not to call her since she was going to try to go to sleep early, but she thanked us for thinking of her," says Sarah writing on her clipboard. "Nanette won't be here because a close friend of hers died. It's a horrible story..." says Bob.
>
> – socio-emotional group, TN

Collectively, members and facilitators work together to account for missing persons in the exchange above. Similarly, when the facilitator has not been informed of a missing person's whereabouts, oftentimes fellow group members can account for one another's absence:

> When Diane, the professional facilitator, enters the room, she says as she closes the door behind her, "Haven't seen you in two weeks Bianca, and Gerald it's been a couple of weeks. We've got a big group tonight. Where's Martin?" "Remember what he said last week? He's going to save his energy so he can go outside tonight and watch the eclipse," says Antonia.
>
> – socio-emotional group, TN

Although Nancy is absent this particular week, Mary Pat, a fellow member expresses her concern for Nancy's speedy return:

> Sarah runs through the list of people who are not here. I notice that she has an attendance sheet where she writes each person's name, checks off their presence or writes down a reason for their absence. My name goes on the sheet as well. She runs through a list of absent people who are considered members of the group, not all the names of whom I recognize. "Nanette's not here because she's getting chemo and that's a good thing, " says Sarah. "We need to get Nanette back in here to talk about her family," says Patryce firmly.
>
> – socio-emotional group, TN

Though the reason for Nanette’s absence has been explained, fellow member Patryce still expresses her worry about Nanette’s unaddressed family issue.  Even though Katie happens to be in the building for another meeting, she still makes sure to show her face in group:

> A tall, heavily-made up woman in a tight black pantsuit sneaks into the room and squeezes herself between Pam and Judy. She looks like she has a notebook and a couple of other folders in her hand. "Hi Katie," Sarah says. "Hi. I just wanted to come in and say hello real fast before I had my Team Convene."
>
> – socio-emotional group, TN

Katie does not return to the group for many weeks, but she arrives unexpectedly at an evening group meeting.  Many seem to know she has been absent due to her stem cell transplant.  Her return seems to suggest her adherence to the attendance norm and her desire not to worry the group:

> ...[T]he group switches gears.  Katie has returned to group after a prolonged absence due to receiving a stem cell transplant. I do not know much about her condition other than what I can tell from her appearance. She looks young, perhaps early thirties, and wears a big teased blond wig. I also know that's she runs every day, which I can hardly believe given that stem cell is often a last resort sort of procedure.
>
> – socio-emotional group, TN

The following remark appears to reflect the underlying sentiment behind accounting for one’s whereabouts when absent from group:

> Sarah the professional facilitator turns to me, "Isn't this group incredibly different than the Thursday night group?" I nod my head, but I really do not want to be put in the position of comparing groups.  "I hate it when I have to miss a day, I truly do. And I worry when other people don't show up to group," continues Patryce. Once again, the group discusses the absent members and speculates as to their whereabouts this evening.
>
> – socio-emotional group, TN

As members file into the meeting room, oftentimes they and others express their pleasure at seeing one another or welcome a newcomer to the group. Arguably, this welcoming norm was the one that allowed me to observe these groups in the first place. Ann Marie has just been diagnosed with a recurrence and no one really expected her to come tonight. Keith, a member and her boyfriend whom she met in group, accompanies her:

> Ann Marie and Keith enter together and all of us rise to our feet almost in unison. "You came!" exclaims Fern, the professional facilitator. I rise because I am occupying a spot on the loveseat and want to make room for one of them to sit down. I see that Jeanne has begin to cry as she embraces Ann Marie. "Good thing you got here when you did. Ed was starting to get out of control. He was going to start making stuff up," says Bob hugging Keith. I move out of the way as group members hug both of them...
> – socio-emotional group, TN

A few months prior to Ann Marie's recurrence, Keith had been gone on vacation and become ill during his absence from the group. Fern, one of the administrators of the cancer support group organization, is a cancer patient herself who recently underwent radiation. She happens to be in the room talking to Sarah as the group gets underway. Members express their pleasure at seeing both of them:

> ...A few people are already seated and talking. Keith is here tonight after having been gone since before Christmas. Sarah, tonight's facilitator, and Fern, [the administrator], both seem elated to see him back. "We've missed you!" exclaims Fern who gives Keith a big hug. "Good to be back," says Keith somewhat bashfully. "Good to see *you* back to your usual self," says Mary Pat smiling at Fern. "Yeah, I don't glow in the dark anymore. Nothing like a treatment that makes you glow for a while. I couldn't hug anyone while I was still radioactive. I was feeling a little [uses a Yiddish word] not being able to touch anyone. That's a Jewish word for feeling _." Fern rolls her shoulders and sticks out her tongue in disgust.
> – socio-emotional group, TN

Likewise, Caroline had been ailing and consequently missing from group for many weeks. Her dramatic entrance into the group seems to demonstrate her genuine affection for each of the people present, including me, and her gratitude to be back on her feet again:

> Caroline and her husband Jim stride into the room at 2:45pm [group started at 2:00pm], interrupting Paulette. Making a grand entrance, she [bursts through the door], goes down the far side of the table hugging Gail, Paulette, May, Fred, and then comes to the other side of the table to hug Becky [the professional facilitator] and me. There is a seat available at the head of the table and she takes it. I move over next to Becky to allow her husband to have my seat so that he may sit next to his wife. He sits for only a moment before leaving the room for much of the meeting. [Where he goes is unclear.] "Oh he's just off doing his own thing," she says waving a hand in his direction.
>
> – socio-emotional group, FL

The warm greeting expressed towards fellow group members and facilitators was also extended to those whom group members knew less well, such as the volunteers and me:

> The volunteer replacing the receptionist [of the support group organization] enters the door. "Monica! Good to see you," says Fern warmly greeting her. "Sorry I'm late," she says sheepishly. "Sorry? You're a volunteer for god's sakes. We're lucky to have you at all," replies Fern.
>
> – socio-emotional group, TN

> Mimi and the [support group organization’s] secretary appear to be conferring over something when I enter. Mimi enthusiastically greets me and says, "I am glad you're here again this week!" I round the corner to enter the group room about five minutes early and see one other woman seated in the room. I sit down in a chair across the room from her. We exchange greetings and she asks me, "So how much longer do you have to do this [come to groups] for your class?" I explain that I am sitting in on cancer support groups for my Ph.D. dissertation and that I have been doing so for almost two years. Her face reflects a look of surprise. "How's it going so far?" she asks. I tell her that I feel really lucky to get to attend groups as part of my research because I find them so interesting....
>
> – socio-emotional group, TN

This norm reflects the desire to acknowledge each person in attendance in the support groups, whether a member, guest, or facilitator.

Another procedural norm dictated the round of introductions that occurred at the outset of all the groups. Introductions or, as seen in the next section, announcements usually signaled the formal beginning of the support group meeting once all persons were greeted. This norm ensured that all present were identifiable, whether a cancer patient, family member, guest or facilitator.  In the breast cancer support group, the women are seated around a u-shaped table configuration, introducing themselves:

> "Okay, let get going," says Laurel [the lay facilitator], trying to get back to the original task at hand.  She starts the introductions with the woman seated to my right and moves away from me.  A total of twenty women [not only give their names, but also] describe their surgeries and time since their last treatment or surgery.  A few women are still undergoing treatment, either radiation or Tamoxifen.  The longest time from diagnosis was five years.  Several women announced that they were celebrating year or half-year anniversaries since their diagnoses.  Their [introductory] comments included: "I had a lumpectomy in November and everything looks great"; "I wanted to be around long enough to spend my husband's money"; "I am a five year breast cancer survivor and for my five year anniversary this past summer, I rewarded myself with [breast] reconstruction"; and "I am doing just fine."  In sum, the medical procedures undergone by this group of women include lumpectomy, lymph mapping, lymph resection, mastectomy (single, double, and prophylactic), breast reconstruction, radiation, chemotherapy, and bone marrow transplantation. The groups cheers...
>
> – informational group, FL

Perhaps because this was a support group focused on a single type of cancer, women felt compelled to give further distinguishing information about themselves in their introductions. Even though introductions were over by the time Bob joined the group, he introduced himself to me anyway:

> Bob bursts through the door and shouts loudly, "Well, hello, everybody!!" He immediately spies me, walks over, and gives me a vigorous handshake,  "Hey there, I'm Bob." We've actually met before, but I introduce myself anyway. He plops down into a chair and continues talking in his booming voice [about his recent doctor's appointment]...
>
> – socio-emotional group, TN

Bob knew everyone else in the group already, but because I appeared new to him, he conformed to the procedural norm and introduced himself.  I took the initiative to uphold the introductory norm with Gayle, whom I did not know:

> We [the other members and I] talk casually and are joined by Gayle who seems somewhat surprised to see me in the room. I introduce myself to Gayle who appears friendly, but frail. When Becky, the professional facilitator, returns to the room, she once again introduces me and again asks the group's permission to have me be present....
>
> – socio-emotional group, FL

Because I did not want to be mistaken for either a member or a facilitator, I abided by the norm and made my identity known. In other instances, the facilitator would make a point of introducing a guest, particularly a speaker for that meeting:

> “We've got some things to talk about, but we'll wait until the end of the meeting as to not waste the doctor's time," says Eddie, the lay facilitator. He introduces the physician, by launching into a long list of his past educational and professional accomplishments. Eddie also adds the doctor will be soon married in the next couple of months. The doctor is a medical oncologist here to discuss the hormone refractory period. "This is a good group -- they ask lots of questions. You've got on a tie, but we're also real informal here," says Eddie to the doctor.
>
> – informational group, TN

> I interrupt the man next to me to see if he minds if I plop down in the chair next to him. He comments on my being alone and welcomes me to take a seat beside him. I feel the need to tell him that I am a graduate student who sits in on this meeting regularly. He then introduces his wife sitting next to him and his sister and brother-in-law on the other side of me visiting from Texas. I shake hands with them all. "I thought it would be easier to just bring them to the meeting instead of me telling them about it later," the man says. [There does not seem to be much socializing going on before the meeting.]
>
> – informational group, TN

Mimi, the professional facilitator, eagerly runs through a long list of announcements, forgetting introductions. Fran notices the norm violation:

> ....”That's another good one [class]. Okay, I am through talking. It's your turn. Who wants to start?" says Mimi, the professional facilitator, clasping her hands together, pushing herself back into the couch. She looks around the room with a smile. "Who didn't get a chance to talk last week?" she says prodding people to talk. Fran points to me. I quickly

> realize that she was not present last week when I introduced myself to the group as only a graduate student and not a person with cancer...
> – socio-emotional group, TN

Over time, group members became so inculcated into the progression of group norms that they still abided by procedural norms even in the absence of the leader. In this instance, the facilitator runs late, so the group finishes the introductions without her:

> Diane, the facilitator, arrives a few minutes late. Bianca says, "We went ahead and started group without you." "Certainly sounds like you have. You all don't need me," she says taking a seat. "That's right, we're self-facilitated," says Martin with a smile. "Oh, I like that word, self-facilitated," says Bianca. "Well, I guess that means you can just go on home," says Martha. "I suppose so," says Diane good-naturedly.
> – socio-emotional group, TN

Another means of getting the groups formally underway was the rundown of announcements, usually provided by the group leader. Procedurally, annoucements occurred toward the beginning of the session and might take any number of forms including outside activities, information about a fellow member, and administrative tasks. Sharing announcements kept group members informed about pertinent information and activities. Sarah, the professional facilitator, reiterates an announcement from last week regarding the merging of two support groups this evening:

> "I know it's early and not everyone is here, but remember last week I mentioned that the post-treatment issues networking group would be meeting at the same time? We thought that because so many of you in here are dealing with post-treatment issues that we would see if you wanted to have a joint group with them. That's only if everyone in here agrees, otherwise we can hold our regular meeting. They don't start for another half an hour anyway," says Sarah. "Does that mean you get to go home early?" jokes Bob. "No, I'll still be here along with the Fern [the facilitator of tonight's other group]. Also, if you don't want to combine groups, anyone who wants to attend the post-treatment issues group is welcome to join them," Sarah says looking around trying to gauge reactions. "It doesn't matter to me," says Jeanne.
> – socio-emotional group, TN

Because many of the members of the regular cancer support group have issues overlapping with the post-treatment group, Sarah tries to combine the two for their benefit. She does not, however, make a unilateral decision on behalf of the participants. Their input, not hers, determines whether or not the group will alter its format for one night. If even one participant had objected, she would have conducted the meeting as usual.

Laurel, the lay facilitator of the breast cancer group, struggles make her announcements over the socializing and greetings of the group. The group has some trouble acknowledging the start of the meeting, although she persists:

> "Okay, I also have to tell you all that we're losing this room for our meetings, possibly as early as October." A murmur of discontent fills the room. Laurel, the lay facilitator, raising her voice to be heard, says, "We've got a super program in October. A RN/Ph.D. will speak to us about getting well and staying well. She uses a holistic approach that integrates the medical, spiritual, and the emotional." Again, voices rise. "Before we break briefly, let's go around the room and tell each other about our cancers. Then, we'll break and afterwards divide up by surgery for discussion." Before anyone can speak, Laurel adds, "One thing we tell this group is participate if you want to, but you don't have to if you don't want. We want you to be as active as you want."
>
> – informational group, FL

In making her announcements, Laurel also comments on the degree of participation expected by the group, further guiding the behavior expected from the participants. Participants do not have to speak if they are not so inclined. Eddie, the lay leader of the prostate cancer group, nearly forgets to make his announcements before letting tonight's speaker begin his remarks:

> Eddie tries to get the group's attention quickly before switching gears [from socializing to the speaker]. "Real quickly now I have few things I want to say. I have some videos up here on prostate cancer for anyone who wants to take one," says Eddie reading off the names of each. "I hope that everybody got one of these pamphlets. [He holds one up]. There are a pile of them in the front here. It's about a live broadcast on prostate cancer we're talking about. If you want, please take one to a friend...."
>
> – informational group, TN

A few of the members of the breast cancer support group have some announcements of their own that they wish to share with the rest of the group:

> A woman sitting a few seats down from Laurel (the lay facilitator) holds up a pair of athletic socks with a pink ribbon on them. She says that she can get them for $3 through the Susan G. Komen Foundation. Yet another woman announces to the group that breast cancer stamps are available at the post office. The woman seated next to me says, "I think we need to name our group Bosom Buddies. I mean right now we're only known as the breast cancer support group." The comment elicits considerable laughter from the rest of the group. "Now let's have some discussion on this, " says Laurel, laughing. "We actually have two suggestions either Bosom Buddies, otherwise known as the 'BB Ladies', or the 'Pink Ladies'." The woman next to me leans over to me and says, "Or we could always name it 'Boobs Galore'." We [all] laugh. Although the suggestions prompt considerable discussion around the room, no decision is made....
>
> – informational group, FL

The procedural norm of making announcements provide the opportunity for all to share information that they think may be of interest or assistance to others. In particular, cancer patients and leaders seem to be particularly interested in announcing cancer-related events or activities in which they want others to participate. On occasion, announcements digressed as members or facilitators solicited others for their involvement in an activity, as seen in the breast cancer group below:

> "Also, we need three cancer survivors of varying ages to model at a fashion show [I do not catch the name of the sponsor]. So before leaving, if you're interested, leave me your name and number. Speaking of fashion shows, we want to do one at our mother-daughter tea. I thought that we'd all wear pink [the adopted color of breast cancer patients and their supporters] and give prizes for the most creative outfit. If you've got any comments, please express them now because we're trying to finalize our plans for next week."
>
> – informational group, FL

Simply announcing the upcoming events does not prove to be enough for Mimi. Although some may be reluctant, Mimi, the professional facilitator, works hard to entice participation:

> As a few more people trickle in the door, Mimi makes a couple of announcements. "We've got our third annual Jokefest coming up on August 3rd – everyone mark their calendars. We had so much fun last year, I can't even tell you [how much]! People tell the raunchiest, funniest jokes you've ever heard. Of all the things at the [support group organization] , this one is my absolute favorite. I even cancel all of my private patients that night. Last year I told this group about it and only Mary and Linda went. They came back and raved to the group and people said, 'oh I really wish I had gone.' Well, go! Last year I actually won the prize for raunchiest joke. I also have a flyer here for meditation and survivorship. I've been saying mediation all week instead of meditation. This one is a really good one -- it's done by [another facilitator]...and she is so good...."
> – socio-emotional group, TN

Both the members and the facilitator use some heavy-handed persuasion to get each other to commit to attending a cancer support weekend meeting:

> "Before I forget, how many of you have sent in your registrations for the "We Can Weekend"? Becky (the professional facilitator) says pointing her finger at the others. "I've only received about an eighth of the number of registrations I hoped to get. I've got about 25 and I am hoping for 200." "We haven't sent our registration form in yet, but we're definitely going," says May. "It's still real early yet," adds Gayle. "So are you going to go, Paulette, or what? Is your family coming in town?" asks Gayle. Paulette seems to hem and haw about going. "I might just go on Saturday, so if your family wanted to drop you off I could bring you back," says Gayle. "I know I could get a ride there. That I know for sure," says Paulette. "Just let me know. I might just go for the whole weekend who knows!" Gayle replies. "Oh yeah, it's such a great weekend," says Caroline as everyone seems to be examining their brochures. Paulette begins to tell a long, rambling story about why she will not be able to attend..."Don't you tell me you're not going to go, Pauline," says Carol in a loud, stern voice. "You can't miss it. It's the best weekend of the year...."
> – socio-emotional group, FL

Members are not only expected to attend group and group-sponsored activities, but also to demonstrate a desire to fraternize with each other outside the usual support group meeting.

Once greetings, introductions and announcements had been made, the emotionally-focused groups engaged in "checking in." This activity constitutes the "meat" of groups where members have the opportunity to share issues or problems and to ask questions of each other. In this portion of group, one may observe members offering social support or asking for coping assistance in response to these problems and issues (as will be discussed in the next chapter).

Much of the subsequent group conversation originates from this activity. Either members or the facilitator may initiate the process of checking in or sharing with each other. In the following exchange, the facilitator prompts Desiree to check in first because she has yet to update the group on her recent mastectomy:

> “Tell us what's happening with you," says Mimi smiling looking at the rest of the group. "You just had surgery," says Robin. "I just got out of the hospital and here I am. I went in at 10:30 in the morning and was out and in recovery by 12:30. I woke up to this nurse screaming my name, DESIREE! DESIREE! WAKE UP! I was so out of it, I didn't know what she was doing," says Desiree. "That sounds lovely," says Mimi. "I guess they wanted to rouse me from the anesthesia. Well, it worked. Then I had Delia, you know Delia," she says looking across the room at Robin and Fran. "She used to be a member of this group," explains Mimi to the rest of us. "You know how you are [after anesthesia], you fade in and out. You can't help it. Delia yells at me, 'I've been here since 5:30am. I just want you to know how long I've been here, okay.’ I was like, geez I get the picture Delia. I felt like I had to entertain her because she came. I guess that wasn't so bad because in talking with her I began to feel more awake...”
> – socio-emotional group, TN

Desiree’s recollection of her surgery allows her to vent to the group about the fellow member who accompanied her to the hospital. Consequently, check in serves as more than just a factual recounting of problems or issues. Fellow group member Bob prompts Mary Pat to talk about herself, giving her the opportunity to share her frustration:

> "Patty, how are you doing?" asks Bob. She laughs and shakes her head,"Oh I'm fine, fine." "What did they decide about that wound of yours," probes Bob. "I was supposed to have the surgery to sew up my wound [from her mastectomy] on Feb. 26th. I went to see another doctor [for a second opinion] who told me that I'll need two surgeries." "What?" exclaims Bob. "I felt so devastated to hear that. This doctor tried to tell me that he had the utmost respect for my first doctor,” says Mary Pat. "You know the Patryce had to have four," says Jeanne knowingly.
> – socio-emotional group, TN

Diane, the professional facilitator, remembers that Martha was due for another round of chemotherapy this week:

> "Martha, how are you feeling?  Weren't you supposed to have your last chemo this week?" asks Diane. "I feel tired, but otherwise I feel completely fine.  I was supposed to have my last chemo already but my [blood] counts were too low, 2.5, and they needed to be at least 3.  I was actually disappointed that I couldn't do it, believe it or not. You get yourself all psyched up to be sick for a week and then this big letdown," says Martha. "Are you going to try and reschedule it for the following week?" asks Diane. "No, because then I'll be sick on Jacob's [her seven year old son] birthday.  I rescheduled for the week of April 7th.  I have to say that I am happy not to feel completely sick [on Jacob's birthday] for once." [I believe she has said that she has been ill from chemo on her little boy's birthday the past two years.]
>
> – socio-emotional group, TN

Martha provided not just a factual response to Diane's question, but shares her emotional response (disappointment) at not being able to receive her chemotherapy as scheduled. The norm of checking in elicits a wide range of feeling and information as members discuss their reactions to the events in their lives with the rest of the group.  In turn, members and/or the facilitator may express their own reactions to one's check in.  Becky, the professional facilitator, tries to galvanize May and Ed into action regarding the lump on May's chest:

> "May, how's your throat?" asks Caroline with her hands clasped. "Fine, fine," she says, looking over at her husband. "She goes back to the doctor on October 18th," says Fred. He explains that May has a lump in her chest close to the collarbone and at the next visit the doctor will perform another x-ray and MRI.  As he talks, she points to the lump's location.  Becky asks if they did not try to see if May could get in to see the doctor any earlier. "I hate to be a pest about it. I know that they're so busy and everyone wants to get in earlier," says Fred. Becky asks them if they thought about getting another doctor to read her report. "Where did you have the chest -x-ray done?" asks Becky.  "Here at Halifax," says Fred. Becky starts scribbling on a piece of paper. "Why don't I see of Dr. X will take a look at the report. I think I can pull it up on our computers and I'll give it to Dr.X's nurse for him to read." Becky puts the piece of paper into her pocket.
>
> – socio-emotional group, FL

The check-in norm applies to all present members, although some members' opportunity to speak may curtailed due to another member's more pressing issues.  Gerald's pronouncement about his treatment diverts the group from inquiring further about Bianca's mild illness:

> "Bianca, how have you been?" asks Diane settling into the couch. "I've been doing fine." "Did you have the flu?" asks Diane. "No, not really I had flu-like symptoms more than anything else”...."Gerald, you had the flu, too," says Diane. "I had flu-like symptoms, but I know it didn't have anything to do with the flu. I went for my chemo this week and my blood work was really abnormal. I've been having all this chest pain up in here [he points to his chest] and all along here [he points to his side]. It's the same way I felt before I got diagnosed with cancer. The doctor sends me for a CAT scan in two weeks. It doesn't look good. My original cancer was in my colon and in my bladder...I've been dealing with this for a year. But you know what? I'm not doing any more. I've done everything [I was supposed to do] surgery, radiation, lots of chemotherapy. I want to enjoy the rest of my life and up until now I haven't been able to yet."
>
> – socio-emotional group, TN

Gerald stuns the group with both his news and his reaction to it. A few weeks later, Diane begins check-in, starting first with Gerald:

> "Gerald, what's going on with you? I heard you were having more chest pains," says Diane. "Yeah, uh, I went to the doctor, right? I have been having these pains in my heart for seven months and all that time I thought my cancer had come back. All my blood work came out great. My CEA (cancer marker blood test) was totally normal. Turns out I have a fatty heart and all this fat in my blood," says Gerald.
>
> – socio-emotional group, TN

Following the norm, I ask Gayle about her recent stay in the hospital last week to receive her 24 hour long chemotherapy treatment:

> "Someone else just asked about that and I didn't know what she was talking about. I guess I do it so often I just forget about it. It [the stay] was fine. I like to go in because I get a little break."
>
> – socio-emotional group, FL

Gayle seemed surprised that I was asking about her treatment at all. Members may say as little or as much as they might given others’ more pressing problems, the length of time left in group, and the number of follow up questions from other members.

Where some members need to be prompted to speak about themselves like Gayle above, others seek to claim time for themselves. Members may request time for themselves during check in without prompting from other participants or the facilitator. Debra needs to vent about her children, not her illness:

> "Practice got cancelled tonight that's why I am here. [Rainy, cold night] I needed to come anyway because I have to vent," says Debra. "I've been cooped up all day with the little heathens who we'll probably hear running around upstairs tonight. I am so sick of being asked a million little questions like, 'Momma, can I play on the computer? Or 'Momma, can I play outside.'" [Debra home schools her children and she runs two businesses out of her home.]
>
> – socio-emotional group, TN

Nanette, on the other hand, is debating whether or not to continue her chemotherapy.

> "I've got some things I need to talk about tonight," says Nanette as everyone else takes a seat. Sarah, the usual facilitator, is not here tonight and her replacement has not yet arrived. "How's that chemo goin'?" asks Bob in his usual upbeat tone. "Well, it's not or at least it may not. I'm thinking about not having my third round of chemo. I have felt so sick with my second round of chemo that I just don't know if I can survive a third round. Right now it's a matter of quality of life and I don't have the quality of life that I want to have. I have sat in the same chair for two weeks now and I can't play with my grandchildren. I can't do any of the things I used to do," says Nanette. "We've all been there," responds Keith. Patryce lets out a little laugh as she rolls her eyes upward,"Oh geez, I mean I know exactly what you're talking about. I mean I've been where you are. The fatigue! Oh, the fatigue!," she says. "I am absolutely miserable, y'all...”
>
> – socio-emotional group, TN

Nanette calls time for herself at the outset of check-in. Presumably because no one else had an issue quite as serious as hers, they let her speak first. Debating chemotherapy strikes at the heart of one of the most important ideological tenets of cancer support groups, as I will show below.

If members or the facilitator had information about an absent member, they would update the rest of the group on their behalf during the usual check in. The serious news about Ann Marie’s cancer recurrence supersedes the usual progression of procedural norms:

> When I enter Gilda's, I see Sam, Fern, Jeanne and the receptionist sitting in the foyer talking. As I say hello and reach for the nametags, Fern immediately says, "Ann Marie's had a recurrence. She has a metastasis to her spinal column." I sit down on the stairs stunned....
>
> – socio-emotional group, TN

Fern, the support group organization administrator, does not wait for members to gather in the usual meeting room in order to share the news about Ann Marie. She catches participants, including me, on their way into the building before group starts. Once in the meeting room, Fern forestalls the usual check in process with her dire news about Anne Marie:

> "I need to update you on Ann Marie, but maybe I'll wait just a few more minutes to see if anyone else comes in. That way I won't be repeating myself over and over. Let's talk about something else," says Fern to Mary Pat. Ed then enters the room and sits down next to Mary Pat. "Have you heard anything yet [about Ann Marie]?" asks Fern. "I think they [Keith and Ann Marie] are going to try and make it tonight," says Ed. "How's Keith [boyfriend and support group member] holding up?" asks Fern. "He's doing okay, but I think he's completely exhausted. She's had to get up about every hour all through the night. He's been with her since she went to the doctor last week," says Ed. "So we still don't know the path[ology] results yet, right?" says Ed. "Right. She wasn't going to know anything until later in the afternoon anyway. I went to lunch with both of them earlier today because she was out in Bellvue getting her hair done and she had not heard at that point," says Ed. "Let's wait one more minute to talk about Ann Marie because I bet Bob's coming," says Fern.
>
> – socio-emotional group, TN

Fern’s desire to wait for Bob’s arrival implies that members are concerned about each others’ well-being and want to know the problems facing their fellow members. In following up on a passing comment by Bianca during check in, I ask her why she had received so many shots during her doctor’s visit today. Martin violates this norm with his abrupt departure from the group:

> I ask her why so many shots were necessary. "That's it. I'm outta here," says Martin moving his large frame rather swiftly out of his chair and out of the room. Diane says to me, "He can't take any talk about needles." "I had to go back to the dermatologist today to have the rest of my skin cancers removed...I've got bandages right here [she points to

> her left forearm], up here [pointing to her right shoulder], and on my neck, too. He asked me if I wanted [some kind of surgical procedure versus another for removing skin cancers] and I said I didn't want a big old scar and to do the [latter procedure]. He basically made an incision shaped like an oval and cut out all the surrounding tissue. The incision is about as big as this bandage on my arm [about three inches long]," says Brenda. "Is he going to send the tissue off to pathology?" asks Diane. "No, I already know that these are basal cell because he had biopsied them earlier. He just had to go in and remove extra tissue to get all of it," replies Bianca.
>
> – socio-emotional group, TN

Ostensibly, check-in provides the opportunity for all members to talk, but in some meetings not everyone gets an equal chance to speak. As in Ann Marie's case above, sometimes members have issues so pressing or so involved that much of the check-in time gets devoted to fewer persons or to a single person. For example, Dale struggles with his speech since his cancer diagnosis; consequently he winds up dominating check in during this meeting:

> "All right Dale's had the floor all evening, not giving anyone else a chance to talk," says Martin smiling, but serious. "Uh, I'm sorry. Next time I won't talk so much," says Dale apologetically.
>
> – socio-emotional group, TN

Martin's insensitivity to Dale demonstrates that members do not always agree on who should have the floor and for how long. Caroline voices the realization herself that she has talked too long:

> "Looks like our time is up," says Becky, the professional facilitator, as she checks her watch. "Boy, I really dominated the conversation didn't I?" says Caroline somewhat apologetically.
>
> – socio-emotional group, FL

The norm of check in applies to all members present and even to those absent, but for whom some information is known. Mimi makes clear to Desiree that she will not be permitted to sit silently, thus violating the earlier norm that you do not have to talk:

> "Desiree, let's hear from you. You just got out of the hospital, right?" says Mimi turning to Desiree seated by the door. "I just came here to listen today," says Desiree firmly. "Oh c'mon, Desiree. Tell us what's happening with you," says Mimi, smiling, looking at the rest of the group.
> – socio-emotional group, TN

In contrast to the emotion-focused support groups, the information-focused groups did not adhere to a check-in norm during the main portion of the meeting, but instead adhered to a norm of information provision through the use of invited outside guests. Unlike their counterparts, information-focused groups addressed their constituents' concerns through the provision of information by expert speakers addressing a wide range of relevant topics. The two information focused support groups I observed --prostate and breast cancer – were generally larger and somewhat more formal in nature than the rest of the groups I observed.

Both the prostate and breast cancer support groups consisted of a series of guest speakers discussing topics selected by the group. Here is how the prostate group segued into the evening's speaker:

> [The facilitator, Eddie,] is in the midst of explaining a sheet he wants all members to complete in order to rank their preferences for themes of interest to them related to prostate cancer. Based on people's preferences they will recruit speakers to present on those subjects. Tonight a urologist will be speaking on the subject of sexual dysfunction and related problems as a result of prostate cancer. The doctor is still over at the snack table stuffing his face and has his mouth full when Eddie introduces him and asks him to come forward. All that I catch of Eddie's introduction is that the doctor's name is Dr. Flood and he is a member of some prominent and burgeoning practice here in Nashville. He looks really young and I wonder how the crowd will react to him.
> – informational group, TN

Members may be interested in receiving information, but they want to do so on their own terms. Tonight's speaker makes clear the group's desire for him to keep his remarks informal:

> "Eddie says no slides, so I am just going to talk informally then. What has changed tremendously is the response of chemo when hormone therapy fails. This is where a group like this is great because I hope to get the word out. Most doctors don't know about

> chemo and part of it is our [the medical oncologists'] fault because we're publishing in medical oncology journals." The doctor removes his tie and continues, "It's like a self-fulfilling prophecy..."
> – informational group, TN

The structure of the breast cancer support group varies slightly to include occasional activities such as a meeting devoted to crafts as seen below:

> Laura has to raise her voice to be heard and says, “Our last meeting was devoted to fun stuff [they made Christmas ornaments], but we’re going to get back to our regular meetings....We’ve got a super program in October. An RN/Ph.D. will speak to us about getting well and staying well. She uses a holistic approach that integrates the medical, spiritual, and the emotional.”
> – informational group, FL

The most common procedural norm specific to information-focused groups was that of asking questions after the guest speaker finished his or her remarks. The inquisitiveness of the prostate group is reflected by the comment made by the group’s speaker:

> Prompted by a question on alpha blockers and bladder function, the doctor begins to explain the workings of the bladder. "Alpha blockers open the neck of the bladder, but [vaso-constrictors] like sinus drugs actually tighten the bladder. The medicine [alpha blockers] loosen the muscle tone. It's given to women for incontinence, but it raises blood pressure at the same time." The doctor pauses for a moment, looks around and says, "You guys are asking some great questions tonight. I'm really impressed.”
> – informational group, TN

The doctor makes several remarks during the meeting about the quality of the questions. His observation speaks to the fact that as evidenced by their interest, these men seem to be really well informed about their disease and its related effects. In one rare moment, the prostate cancer group falls silent during one speaker’s remarks:

> The doctor looks around anticipating further questions. After a brief period of silence, Eddie remarks, "This group's not known for its inability to ask questions."
> – informational group, TN

Because the primary purpose of these groups was to provide informational social support, they appear to be much more didactic in their approach to cancer. The men in the prostate cancer support group clearly demonstrate interest in further information, as reflected in their participation.

Although the breast cancer group also employed a didactic approach like the prostate cancer support group, they also seem to be interested in sharing emotionally with each other. Checking in with each other was not a formalized function of that group; thus, sharing about oneself was limited to the informal socializing before and after the group. For example, the first time I attended this group, I noticed that participants were eagerly socializing with each other before the meeting convened. In fact, the lay facilitator herself was so involved in talking with other women that I had another group leader whom I knew try to get her attention so I could introduce myself:

> The two of us squeeze past clumps of women who appear so deeply engaged in conversation that they do not hear us say “excuse me” as we move past them. Laura welcomes me to join them. She seems somewhat distracted by the rising din of conversation all around us. She turns back to her pins [selling breast cancer pins as a fund raiser] and immediately begins talking to another interested customer. This group appears to be very much interested in socializing with one another. I can hardly hear Laura over the voice of the twenty women who are here tonight. When I sit down I notice only one other woman seated by herself not talking to anyone...
> – informational group, FL

During the same meeting of the breast cancer support group, members became so caught up in talking with each other that they forgot they were supposed be talking as a discussion group:

> "Hey, shouldn't we be talking as a group?" says Millie looking around her. "Oh yeah, that is what we're supposed to be doing," says Donna.
> – informational group, FL

Clearly, individuals interested in attending the prostate and breast cancer support groups were those interested in an informational group format versus an emotional one. As will be seen in the next chapter, the group format heavily influences the kind of social support and coping assistance offered by support group members.

During check-in in the emotion-focused group, the conversation often strayed away from cancer related topics to other areas of members' lives. In addition to more serious non-cancer concerns and issues, members demonstrated a need to talk about the mundane, everyday aspects of their lives. These digressions show that checking in really acts as a part of a broader norm of sharing with the group about all parts of one's life, not just cancer. As a result group members appear to become more than just fellow cancer survivors, but friends.

Off-topic conversation covered a wide array of subjects: motorcycles, Mt. Everest, politics, family, bras, breasts, doctors' personal lives, divorce, cooking, babies, Elian Gonzales, history, vacations, jokes, the lottery, sports, bugs, movies, work, television shows, and pets. Perhaps among the most frequent non-cancer topics were family matters, especially kids:

> "Darren and I made two decisions when we decided to have kids. They would never step foot in a classroom or on a school bus. That was it. Hey, at least I don't have to worry about them getting shot," says Debra. "Aren't you worried about socialization?" inquires Martha. "They have a ten year old friend up the street and they go to church," says Debra. "You know we live on a cul-de-sac – for the longest time I had no idea what that meant. I now realize that's French for turn around place. I felt like the biggest idiot," she adds. "Don't feel bad. When I first came to this country I thought people were saying 'culture shack'. You know, people would say they were headed down to the culture shack and I would say, 'oh, cool,'" says Gerald laughing.
>
> – socio-emotional group, TN

Through their discussion of children, group members shared positive news with each other as well:

> "I'm a grandmother for the third time," says Ann Marie beaming. "You sure don't look old enough to be a grandmother! " exclaims Bob. "Yeah, I know. My sister is too, and she's

> younger than me, but anyway..." says Ann Marie with her voice trailing off. "How many kids do you have?" asks Bob. "I've got two boys and two girls," replies Ann Marie. "I thought you just had the two girls," says Bob. "I had twin boys when I was sixteen who I put up for adoption. They got back in touch with me in 1988 and we've been close ever since. So, this latest one's name is Camellia," says Ann Marie. [I am not sure how forthcoming she would have been about her teenage pregnancy had Bob not seemed so persistent.]
>
> – socio-emotional group, TN

Sharing good news opened Ann Marie upon for further questioning about a subject she might not have addressed otherwise with the group.

Members were not the only ones who led the group astray. Here, the facilitator redirects the conversation to the topic of children because several members have their children in the support group organization’s childcare this evening:

> "You've got a little one at home, too," says Diane to Gerald who nods his head. "And you too, Dale," she says looking at Dale. "Mine are upstairs right now. I told them to be gentle up there. They're so big they don't realize how physically rough they can be sometimes," says Agnes. "Will's upstairs," says Dale. "That's right. He's playing with my grandsons right now. I'm surprised we can't hear them," Agnes says. "That boy is amazing, I mean amazing," says Dale about his own son. Somebody says what a great kid he is. "We tried for the longest time. We tried, and tried, and tried, but we were OLD," says Dale with emphasis about trying to get pregnant. "We just couldn't get a son. I mean we couldn't get anything at all," he says with a laugh.
>
> – socio-emotional group, TN

Politics often arose as a conversational digression, giving members the opportunity to debate other subjects. The group begins discussing the recent deportment of Elian Gonzales back to his native Cuba; that topic turns personal for Gerald:

> "Oh yeah, some of these Hollywood stars like Andy Garcia gave the family hundreds of thousands of dollars. A lot of these Cubans are rich. I mean I don't think it's fair that they can just float over here on a raft and expect to become US citizens. People like me have to afford a plane ticket over here," says Gerald. "But you don't live on an island ninety miles away from the Florida Keys either," sniffs Martin. "Yeah, I know that, but not

> everybody gets to have political asylum here, only people from Cuba and Haiti. The rest of us have to apply and wait," replies Gerald.
> – socio-emotional group, TN

Political discussions like the one above allow members to argue and debate with each other about other subjects in which they feel invested. Typically, the conversation during check in wandered between cancer-related subjects and other topics. Both members and facilitators led the group onto other subjects and then took responsibility for redirecting the group back again to cancer. Dori discusses a fellow co-worker with cancer whose physical appearance is worsening:

> “Yeah, she really has to learn how to take care of herself. That’s the one thing I really learned from cancer, that I really had to start taking care of myself better. I have started carrying this water bottle around with me all the time to keep myself hydrated. I have to keep water next to me at night because my throat gets so dry. My hands are really dry now, too. A girlfriend at work gave me some real nice lotion for my hands and I have started to use a special avocado oil soap to wash my face. I thought I was getting the beginning of a cold on Monday. I had a sore throat, runny nose and all that. Then I started taking Echin–, whatever the name is.” “You mean Echinacea,” says Martin. “Yeah, that’s the name of it. I got it over at Rainbow [health food market],” replies Dori. “I’ve started drinking this tea since I have been doing the macrobiotic thing,” says Gerald. “I have been eating brown rice, tofu, seaweed, the whole works!” he says triumphantly. “Your little boy eats that stuff, too?” asks Antonia. “I could never do that.” “I had a real nice juicy roast last night, mmmm,” adds Martin.
> – socio-emotional group, TN

This example demonstrates how quickly the conversation transitions from subject to subject, moving farther and farther away from the co-worker’s cancer and into eating alternative foods. The same group returns to the topic of cancer minutes later by way of Gerald’s participation in a kareoke contest the previous weekend:

> “A woman tried to pick me up last weekend when I did kareoke,” says Gerald beaming. “Carol [his wife] doesn’t know, does she?” asks Diane. “Oh yeah, I told her. Of course I told her. I was sitting there drinking coffee in this bar because I can’t really drink beer. She was looking at me going, come here, come here. [He imitates her beckoning him over with her finger.] I thought hey, women still find me attractive after having cancer. She was pretty good looking, blond, cute. She was from Mississippi and obviously in town to

> have a good time." "He tells everyone he has cancer," Dori mutters loud enough for everyone to hear. "How did you tell her you had cancer?" asks Diane apparently picking up Dori's cue. "Well, first of all I was in this bar drinking coffee instead of alcohol, which probably seemed a little strange. She asked me about it and I said I have cancer...."
> – socio-emotional group, TN

Dori's muttering returns the group back onto the cancer track, prompting Diane to question Gerald further about his chemotherapy. Off topic conversations gave members a break from talking about their illness and allowed them to move onto other subjects at will. Perhaps, too, the meandering of group conversation showed that members are still normal people with normal sorts of problems in spite of their cancer.

Finally, groups adhered to a norm of ending at a specified time. Members could continue socializing (and often did), but they and facilitators mutually understood that the formal meeting had ended. Facilitators or at times members signaled to the group either verbally or non-verbally that their time together had officially expired:

> "Is anyone not going to be here next week, that they know of?" asks Diane. Different voices say yes. I say that I want to tell everyone that next week's group will be my last group for a while. I say that the semester will be over for me and that I am going back to Atlanta to be with my husband. "My sister and her husband live there. Do you remember what he [your husband] looks like?" jokes Martin. I laugh and say barely. "That's good to know," says Diane.
> – socio-emotional group, TN

Diane's final question to the group lets them know that the group is concluding. Similarly, when another support group has surpassed its usual ending time by ten minutes, Sarah, the facilitator, rises to indicate the end of group. Eddie scans the group for any further questions before ending the prostate cancer group:

> "Anyone else?" asks Eddie. "Thanks, doctor, for taking the time away from your practice and your family and helping us making decisions about treatment," says Eddie. The doctor repeats the web site he had mentioned in the beginning of the group. Tonight I count 35 people here, but I see that only 30 names on the sign-in sheet. "Don't forget there are pink sheets and videos for you to take," says Eddie as the room bustles with activity.

> – informational group, TN

> "We always hug each other after group," says Paulette who gives me a huge squeeze. Dorothy also comes over to me to give me a huge hug.
> – socio-emotional group, FL

> Ed stands. I stay back while the rest of the group members exchange hugs and conversation. Paulette approaches me and gives me a big squeeze without saying anything. Caroline grabs me next and thanks me for coming.
> – socio-emotional group, FL

Thus, standing and stretching, a group hug, or asking the group about the following meeting served as mutually understood means of formally ending group. Of course, facilitators could just end as Becky does:

> Becky ends the meeting by reading an 11th century poem penned by Rumi . "[With that]I bid you all adieu," she  says with a smile. "You're kicking us out, are you?" says Eddie jokingly.
> – socio-emotional group, FL

### Emotional, Cognitive, and Behavioral Norms

In the process of coding my data, an unanticipated concept parallel to emotional deviance emerged - cognitive deviance.  Much like emotional deviance, cognitive deviance may be conceptualized as thoughts or beliefs that may be inappropriate or incorrect for the situation. Examples of cognitive deviance appeared in the coding process with much greater frequency than emotional deviance, causing me to realize that cognitive deviance is an important but neglected form of deviance often overlooked in the research literature.

I will turn now to the support group discussion itself and describe how emotional, cognitive, and behavioral norms uphold the ideological beliefs generated by the support groups. These norms will be discussed as they pertain to each of the five ideological principles outlined in chapter three.

### Belief: It Is Important to Follow Conventional Treatment

Norm: One Should Follow Conventional Treatment

Believing that chemotherapy works represents both an ideological tenet of the groups as well as a cognitive norm. Members expect that others will follow a standard course of treatment, as discussed in the earlier chapter on ideology. Sam simply assumes, as most would, that Ella would have completed the usual rounds of chemotherapy:

> Sam and Ella discuss their respective bouts with breast cancer. "I was diagnosed about six months ago," says Ella. "So you must be about done with your chemo," says Pam. "Finished today," replies Ella nodding her head. "Congratulations! That's great news! What drugs did they have you on?" asks Sam. They elaborate for the other in detail the combination of chemotherapy drugs administered to them.
>
> – informational group, TN

Nanette attempts to justify why she should quit her arduous chemotherapy regimen, but Bob uses his own experience to persuade her otherwise:

> "I'm about as ready to die as I am ever going to be. I mean I still have to drive home tonight and something could happen then," says Nanette. "You know who you sound like?" says Julie. "You sound just like Bob did when he first joined this group. 'I'm not going to do that darned chemo," says Julie playfully. "And I did everything after all – surgery, chemo, and radiation. The doctor basically said we've done everything we can for you. Good bye and go have a nice life. I had a huge surgery where they removed all of the cancer and the surrounding tissue. I immediately had radiation and then 45 days of chemo straight. I had to wear this horrible chemo bag holster all the time. Pancreatic cancer is fatal 99.9% of the time," says Bob.
>
> – socio-emotional group, TN

Bob demonstrates that his treatment was even more difficult than Nanette’s and he endured it anyway for a less than promising outcome.

Victoria has been persuaded to do what is “right” to ensure her survival:

> Someone asks her what she decided to do about her course of treatment since at the last meeting she was seriously considering going the alternative medicine route. "I'm gunna do it," she says sounding and acting like a small child with a soft voice and fearful eyes. "I am going to have the surgery and the chemo it looks like." She gathers her self into a small ball on the couch.
>
> – socio-emotional group, TN

Bob reminds Victoria that the group has not always been tactful when one violates the norm of following conventional treatment**:**

> "They've been nice to you. You should have seen how they treated me when I said I wanted to go the alternative medicine route," says Bob. "I don't want to sound like an Amazon or anything, but I did it on my own for three years. I had family and friends and, of course, my church," says Margaret. Jeff returns to the subject of Betty, an absent member tonight. "We have a member of our group, Betty, who did alternative treatments for a year. She did all that stuff – coffee enemas, non-stop juicing all day long. She went to Germany to have a special kind of treatment where they heat your body to a temperature of 105 degrees. Representatives of the US government went in there and told patients that this treatment was not approved by the FDA and was considered to be dangerous."
>
> – socio-emotional group, TN

Bob describes for Victoria a fellow group member's pursuit of alternative treatment, but not without underscoring both the extremity and danger of her actions.

Betty's subsequent death seems to be ultimate confirmation of the group's "correctness" on this particular issue:

> "I have some bad news for all of you. Betty died yesterday," says Fern. [Betty was former member of this group whom I did not meet.] "Henry [her husband] is doing really well and has surrounded himself with family and friends. As most of you know, Betty went the completely alternative treatment way -- heat treatments in Mexico, the Gershon method, juices. She actually became malnourished from all the juicing she was doing and that led to her decline. Her cancer moved from her legs up to her lungs. She agreed to doing the surgery, but she refused any chemotherapy and radiation." The room is silent. "She battled this for two years, but remember she did this all on her own terms," emphasizes Fern.
>
> – socio-emotional group, TN

This last exchange serves as a stark example of what can happen when one strays from accepted thinking of the group. Thus, Betty’s death serves to sustain the belief in this particular norm.

By enforcing the norm of one should follow conventional treatment, members demonstrate their unswerving faith in what they have found to be the most effective means possible of beating cancer. Cancer patients’ own presence in the groups serve as real life examples of its effectiveness in keeping people alive. Violations of the norm illustrate the foolhardiness and even deadliness of pursuing unproven methods, further enforcing adherence to the over arching ideological principle.

### Belief: It Is Important to Take Charge

#### Norm: One Should Take Charge of One’s Illness

Implicit in the exchanges below is the cognitive norm that one should take responsibility for oneself that stems from the ideological belief in the importance of taking charge. Members urged each other to be well informed about their cancer and its treatment to increase the odds of their survival. In Mary Pat’s case, she is informed enough herself to question the practices of health care professionals:

> "What does home health care do?" asks Sam. "They dress my wound for me. I have to change the packing every eight hours [rolls eyes]. When I was in the hospital, I was in the oncology unit, not the surgery unit, so the nurses were less experienced with dressing wounds. I've got what they call wet-dry dressing, so the wound has to be packed in a certain way. This woman came in, put on sterile gloves, took the real puffy kind of gauze, soaked it in saline and then left the room to get something else.' Mary Pat seems to assume that everyone knows the implications of the nurse leaving the room, but no one seems to indicate that they do. 'The gloves?! You know she left the room with the gloves on and came back in?! AHHH!” She rolls her eyes and slaps her leg.
>
> – socio-emotional group, TN

Mary Pat catches the nurse not changing her gloves upon re-entry into her room. The nurse's oversight could have potentially caused Mary Pat's wound to worsen, something she dreads already.

Kate's husband has melanoma that metastasized to the brain, sending them in search of new doctors:

> Kate says that the neurosurgeon unlike the receptionist was great both professionally and personally. "We interviewed three different neurosurgeons and we definitely got the best one," says Kate.
> – socio-emotional group, FL

Interviewing and selecting a doctor gives Bill and Kate sense of control and security over the course of his treatment. Caroline "fires" her doctor and heads somewhere else when he makes an egregious mistake:

> "Can you believe a gynecologist missing ovarian cancer? And he was supposed to be the best they [the local health care system] had to offer?" Caroline says in exasperation. "That's the whole problem -- there are no oncologist/gynecologists anywhere around here! I had to go all the way to Mayo to see one," says Gayle.
> – socio-emotional group, FL

In addition to taking responsibility for receiving quality medical care, members address more threatening issues. Members could distance themselves from the threat of death when it served as a means of thinking practically about one's life and preparing for the future as anyone would. Their matter-of-fact discussion of funeral plans and obituaries seemed to be more a matter of being responsible than expecting an impending death. Thinking about more morbid matters seems to be easier when believing like everyone else, they could die unexpectedly of other causes:

> "I've already written my obituary!" announces Rob. "It says that I won the Pulitzer prize for literary [sic]. I married Hilary Clinton - twice! I lived next door to Monica Lewinsky.

> People will think I led one hell of a life, course none of it's true," he says gleefully. "Belinda, I have made my arrangements, picked out my casket, and planned my funeral. It's not a bad idea," says Patsy seriously. "I agree," says Rob seriously, too. "I've picked out my casket and done all of that, too," says Jeanne. "I agree with you that I need to get my ducks in a row. She [the nurse] could have given me that information in a different way [nurse told her she had six weeks to live]. You never know what's going to happen. I could leave this group tonight and get hit by a car..." says Belinda. "Or fall of a cliff," says Nanette, referring to her friend who died three weeks ago.
>
> – socio-emotional group, TN

Likewise, Nanette's husband tries to use the same tactic on her:

> "My husband said to me that maybe we should go ahead and make arrangements in case something unexpected happens to one of us. I said, 'What do you mean? I've already made my funeral plans. I've picked out the preacher and hymns and even the funeral home. I like that one over there by Centennial Park with the cream colored building and new awnings. I know that doesn't mean much, but it matters to me," says Nanette.
>
> – socio-emotional group, TN

She did not need to wait for her husband to reframe a threatening topic in order for her to make the necessary plans for her death whenever that should happen.

Ann Marie talks about planning funeral arrangements as a means of getting herself organized:

> "Keith and I were lying in bed last night talking --" says Ann Marie. "Because you couldn't do much of anything else," says Bob interrupting her. "Right, we couldn't have sex, so we were talking," says Ann Marie trying to continue. "Hey now, you may not be able to have sex, but believe me there are lots of other things you can do. We can talk after group," says Bob knowingly. "I guess I can still move other parts of my body," replies Ann Marie jokingly. "You bet you can!" says Bob. "Seriously we were talking about the future and making arrangements like I need to make a will. God, I need to just clean off my desk so that if something happens they can find my important papers. My desk is literally a giant heap of papers," says Ann Marie.
>
> – socio-emotional group, TN

Paulette talks about planning her funeral so as not to be a burden on her children and so that she can have it the way she would like:

> "Seriously though, folks, I was at the funeral home making the arrangements for my funeral. My daughter was talking about the funeral of her mother-in-law who lived in New Mexico, but died in Nevada. She said to me, 'Mom, I was actually able to *enjoy* [her emphasis] the funeral because I didn't have to do a thing. She had taken care of everything ahead of time down to the preacher she wanted. I don't want to burden my kids. I told the funeral director that I wanted my funeral to be just like Bill's. You know how Catholic churches use incense? I can't stand that stuff and I told the funeral director at Bill's funeral that I would walk out if they used it. I don't want it at my funeral either. I'll get up and walk out." Paulette literally shrieks with laughter. "What do you care if they use incense? You're dead!" says Maya. "I told my kids I'd come back and haunt them if they didn't run my funeral the way I wanted."
> – socio-emotional group, FL

Kate shares a book on organizing one's death with the group as a practical guide for anyone to follow, not just cancer patients:

> "Before we go, I just wanted to share this book that we heard about from "20/20", not that you are necessarily going to die. This woman is living with terminal breast cancer and she outlines all the things she has done to prepare her family and herself for her death. She made videotapes for her preschool-aged daughter, organized all her mementos, arranged for her living will, and has even made all the arrangements for her funeral. She has taken care of every little detail," says Betsy. "Wasn't she just on 'Oprah' not long ago?" asks Betsy. "Yes, she was. We ordered the book right away. It's really a book for everyone and we highly recommend it." Kate passes the book to Paul and Betsy.
> – socio-emotional group, FL

Group members subscribe to the norm that one should take charge because they believe that only they can be their own best advocate. As members seem to know too well, health care professionals' judgment and opinions can falter. By asking questions, choosing doctors, and gathering research, they attempt to steer the course of their own treatment plan to optimize their own outcome. One should also take charge of other aspects of their life related to their cancers including planning one’s funeral. Members may not be able to control when or where they die, but they can control how their funerals will be handled.

### Belief: It Is Important to Maintain a Positive Outlook

A fundamental cognitive norm of cancer support groups appears to be that one must believe that one will survive beyond one’s cancer. Adhering to this particular norm seems to be an important aspect of what groups do to maintain the emotional well-being of their members.

#### Norm: One Should Try to Think Optimistically and Focus on the Positive

One manifestation of this norm is thinking optimistically. Gayle’s upbeat tone shows that what she has been through has not been as bad as she was led to believe:

> “I am on my three month check-up, so I go back in May for that and uh, I feel good. Seem to be doing well, but you never know with cancer what's happening because, uh, uh the reason I came to this group, as I [said earlier], I thought cancer is going to be so bad. I am going to be so anxious! I am going to fall apart! I have felt wonderful all during my time. People always say once you've found out you don't have cancer any more there are going to be some anxious moments, so I really had more of those than I did during my treatment almost. I was really surprised because I really try to squeeze a lot of things into my time. I thought, wow, I can do my clubs, I can go see my friends, do all these types of things. I try to do a little too much, but basically I feel good.”
> – socio-emotional group, FL

Gayle thought she would be doing worse physically and emotionally during her treatment, and seems pleasantly surprised that her preconceptions were wrong. She also mentions her violation of another emotion norm: one should feel worried about the return of cancer once treatment ends.

Bob appears to be thrilled that he does not have to return to the doctor for further treatment:

> "I saw my doctor and he told me that I never have to come back to him," says Bob. "Really?" Mary Pat and Margaret both say in astonishment. "That's incredible news, Bob," says Ann Marie . "You never have to see the doctor again? Not even for blood counts?" asks Mary Pat skeptically. "Well I have to get blood drawn every six months or so, sure.

> But I don't have to go for any more scans. My doctor said they followed exactly the protocol for my kind of cancer and there's no more to be done. Either I'm going to live or die. With pancreatic cancer, there's no middle ground. My wife just about lost it. She just couldn't believe that there was nothing more to do," says Bob.
>
> – socio-emotional group, TN

Although he seems to interpret the end of his doctor's appointments as a positive for his survival, his wife seems aghast that doctors have no further treatment for Bob whose form of cancer is almost always fatal.

Dale, who has brain cancer, can barely speak understandably, but maintains a remarkably cheerful perspective on his life:

> "Dale, I just want to say to you what an inspiration you are to me. I know that God is teaching me humility when I look at you," says Gerald raising his fist. "You inspire me too, Dale. When I am sitting around feeling like crap, I think about you and I think, stop your whining and get over yourself," says Anne. Dale smiles and stutters, "I think about that kid on TV who I saw with the legs [meaning the prosthetic legs] and I think I am pretty lucky. I don't have time to ---." "Get all the words out or worry," says Diane, the professional facilitator, teasing Dale. "Yeah, well both," he says laughing.
>
> – socio-emotional group, TN

Dale's upbeat attitude inspires his fellow group members to change their attitudes as well.

Paulette's daughter Sally talks about the importance of maintaining a fighting spirit:

> "I mean mom's got cancer and it could be a lot worse. She's lucky. And I myself believe in a positive attitude, you know? You can lick anything and even if you can't lick it you can at least keep up the spirit and do the best you can do with what you've got," says Sally.
>
> – socio-emotional group, FL

In keeping with thinking positively, members work together to dismiss ordinary symptoms that could be interpreted as something more serious:

> "What did the doctor say about the bump on your wrist?" asks Fern. "Don't you know on my scan I had right hand tucked under my fat thigh and you can't see it. The other hand you can see perfectly. I haven't said anything to the doctor yet. It showed up in July and more recently has grown bigger," says Ann Marie. "It could just be a calcification, I have one on my wrist, too," says Geoff. "It could be a million things," nods Fern.
> – socio-emotional group, TN

Other non-member participants worked to reinforce the norm of optimistic thinking. During a support group aimed at lymphedema (severe swelling caused by the removal of the axillary lymph nodes), the professional facilitator catches herself:

> "I hope that I am not scaring anyone here by discussing lymphedema. I'm sure you all have read so much already and we're all at risk for all kinds of things. I just want you to be informed as a means of prevention."
> – informational group, TN

The professional facilitator fears she has given out too much information and worries that she may have scared the participants in the meeting. Similarly, the guest speaker at the prostate cancer support group discusses the implications of heredity, but carefully couches the information he gives:

> "It's probably best to tell [male relatives] that they are at increased risk anywhere from a two to six fold increase for developing prostate cancer. Now before they run out and make a will [after hearing that information], you have to give them the numbers for prostate cancer....Of course, the bad news is that you have cancer, but the good news is that prostate cancer isn't a bad one to have. If God lined you up and told you to pick one [a cancer], prostate would be a good way to go..."
> – informational group, TN

Becky, the professional facilitator of one the socio-emotional groups tries to generate group discussion using an optimistic frame for thinking about one's life:

> "Today I want to talk about hope -- what it is, what it means to you, how to find it," says Becky. "I think Bill had hope," Pauline says of her late husband. "I'm better off than I have ever been [even after cancer]. When Bill was alive we were always on a budget. Now I take money out to buy groceries and other things, I've even stopped playing the Lotto. How about you?" Pauline says swinging an arm in Mayme's direction. "Well, I hope that we'll both live together for a long time to come," Mayme says looking at her husband, Ed. "We've been together 57 years -- he's 84 and I'm 80. We're both healthy finally." "We are?" says Ed in a joking tone....
>
> – socio-emotional group, FL

Members describe their interactions with health care professionals outside of group who threaten this belief. Bob talks about his oncologist with whom he happens to be close personally:

> “He's a good friend of mine. He came to see me every day or almost every day while I was in the hospital. He's definitely a no nonsense guy and he'll tell you just how it is. He told me that at most I only had two more years to live and he said it just like that. I said, 'Charlie you son of a bitch! I didn't want to know that!'" says Bob.
>
> – socio-emotional group, TN

Although persons within group may try hard not to scare each other, health care providers have a different approach:

> "It's hard to hear that for the first time. I almost think it doesn't start to sink in until the second or third time they tell you," says Patsy. "That's true for me. Plus, there was the study that showed that stem cell transplant made no difference in breast cancer patients. My doctor said that for my cancer I had no other choice if I wanted to live. We flew to Chicago for a second opinion and for some reason they were better at communicating with me. They seemed to take more time and be more understanding. There was something definitely different. I think the third time they tell you, you start to believe it," says Karrie.
>
> – socio-emotional group, TN

To the dismay of support group participants, doctors and nurses in particular violated the norm of optimistic thinking perpetuated by the group.

In the following excerpts, members discuss the possibility of their own deaths. Perhaps because of the fundamental desire to believe that cancer is only a temporary state of illness, the possibility of death arises infrequently in the course of support group discussion. Many of the participants had never thought about death before their cancer diagnosis and, as these excerpts show, they still do not want to think about it:

> "I was having a skeletal x-ray of my hand and I was talking to the nurse about my cancer and she said to me, "Well that kind of cancer has no cure anyway.' I couldn't believe she said that to me. I was like, 'I'm gunna die?' We never talk about that," says Jeff. "You won't die. You won't die," repeats Julie firmly and matter-of-factly with her lips taut and arms folded in front of her. "I really love my life. I don't want to die. Besides I haven't been to Las Vegas yet," he replies.
>
> – socio-emotional group, TN

Jeff's nurse violated the belief that other support group members hold and the likelihood of his possible death came as a rude surprise. Until the nurse had been cruelly blunt with him, Jeff had not seriously considered death to be an eventuality for him, despite the seriousness of his cancer. Debra, who has melanoma, echoes a similar sentiment below:

> "I home school both my kids and run two businesses out of my home," says Debra. "You don't ever get a break, do you?" says Diane. "No, I don't. Derek and I pass each other in the hallway at night and I say, 'Do I know you?' We barely get a chance to talk during the day, so we wind up talking in bed. Then we have to talk about what to do if I die or he dies," says Debra. "You mean pillow talk is the only time you have to discuss such important matters," says Diane. "Right," says Debra. "I am 25 and I have always thought growing up that I was invincible. I was never going to die. I still don't feel like I am going to die."
>
> – socio-emotional group, TN

Caroline, diagnosed with ovarian cancer, has already outlived her prognosis by six years:

> "I never thought about cancer before December 1992 and then the doctors opened me up, told me that I had two weeks to live, and zipped me back up. You never think that you'll find yourself in that kind of situation and I did. No one should ever be put in that situation. My husband I and went up to Mayo where they cut out as much as they could and then told me that I had at most three years to live."
>
> – socio-emotional group, FL

The doctors had been wrong about her survival, so Caroline thinks she may have beaten her illness. Group members want to believe that they will have a positive outcome and they continue to aspire to a high quality of life. However, they still contend with threatening thoughts about aches and pains being recurrences of cancer or the spread of new cancer rather than more obvious explanations. Violations of cognitive norms to think positively may be more threatening, thereby undermining the well being of the group. As a result, members appear to have a vested interest in correcting inappropriate assumptions or conclusions:

> "I had something pretty horrible happen to me this week that I want to tell y'all. I called my regular doctor's office this week, not my oncologist mind you, and got one of the nurse practioners on the phone. She said, 'I don't know why you're worrying about all this. You only have another four to six weeks to live anyway and you need to worry about making the appropriate arrangements.' I almost hung up on her, but instead I thought it was important that I tell her how I feel. I told her how incredibly inappropriate it is for her to be telling me over the phone how long I had to live. The only person who can tell me that is my oncologist, a doctor, not some nurse practitioner who doesn't have enough medical training. I talked to my doctor and said that I never want to see that nurse when I come to see him. See, I love my doctor otherwise I would have switched doctors and never gone back there if it weren't for him. If they put me in a room by myself with her, I will not be held responsible for what happens. My mother got on the phone and said, 'How dare you tell her that she only has four to six weeks to live! What right do you have to give anyone that prognosis?!'"
>
> – socio-emotional group, TN

Norm: One Should Try to Live and Behave as Normally as Possible

Part of maintaining optimism is trying to maintain a normal life, however unrealistic that may be in some cases. Mary Pat still forced herself to attend her daughter’s swim meet even though she felt physically bad:

> "I had to go to my daughter's swim meet this weekend and the meet lasted Friday, Saturday and Sunday. I wanted to be there for my daughter, but I had to sit there feeling miserable. I kept running into people who told me how good I looked and I wanted to scream." "Well, I take it all back then. You look like shit," says Rob humorously referring to his earlier compliment. Everyone else laughs as Mary Pat shakes her head with a smile.

> – socio-emotional group, TN

Nanette expresses her deep disappointment about missing this year's Super Bowl. Her chemotherapy has left her immune-compromised, leading her to shun large crowds of people:

> "I am so bummed out that I can't go to the Super Bowl this year. I had been looking so forward to it," says Nanette. "Trust me. That's the last thing you want to be doing," says Kevin. "I did something similar and it almost was over for me." Bob says, "Yeah, I know you're right. I was [in the Titans' stadium] for the Music City Miracle and it was right after I had the port put in. My son was so excited that he picked me up and gave me a huge bear hug. [I hear various group members suck in air.] As soon as he did it he immediately regretted it immediately. Then the woman behind me gave me a big old slap in the same place and I thought I was done for at that point," she says.
>
> – socio-emotional group, TN

Even had she wanted to go, the experience probably would not be as enjoyable as it might have been had she been in better health. The responses of her fellow group members also reinforce the ideological principle of taking care of oneself.

Agnes still snuck a cigarette during her hospital stay for her mastectomy:

> "At Vanderbilt the hospitals rooms feel like a jail cell they are so small. I thought I was going to lose my mind when I was in there. Plus, they want the door shut, making me feel worse. They told me I could get up and walk down the hall, but I went outside to have a cigarette," says Agnes. Diane looks amazed, "Here you are immuno-compromised and you went outside? To have a cigarette?" "Hey, I wore a mask. What can I say? I didn't sit around any other people. So I am sitting out there having a puff and here comes my whole team of doctors. They must have had a meeting or something to go to and there I was totally busted," says Agnes. "Did they see you?" asks Diane. "Yeah, but what could I do?"
>
> – socio-emotional group, TN

Agnes's desire to maintain some semblance of normality for herself happens to violate the ideological belief that cancer patients need to take good care of themselves. In other words, the belief that it is important to be optimistic does not necessarily mean that one should behave like someone without a life threatening illness.  Wanting to resume the life one had prior to cancer may be possible eventually, but for certain behaviors should obviously be delayed until one’s physical condition improves.

Other members talked about just wanting to live long enough to engage in the normal activities parents do with their children and see them grow into adulthood:

> "Yeah, I just want to get back to the question that I asked earlier. You know what I want to do more than anything else in the world?  I want to see my son grow up.  More than anything else I want to do that.  We were taking a car trip to Dallas and I was sitting in the back with him just staring at him. Sometimes he just stares at me, too, but I was thinking please God just let this moment never end. I want to stay just like this forever, but then I know that's really selfish and Carlos needs to grow up,” says Gerald.
>
> – socio-emotional group, TN

> "I know how you feel, Gerald. I don't even go anywhere I can't take Jacob. If he can't come, it ain't worth going. You're an older parent, too. I was 42 when I had Jacob and I'm a single mom. His dad has never been a part of his life ever. There are so many things I want to do with him yet. I want to ride on an airplane, I want to ride the train, I want to take him to the beach, I want to take him to Disneyworld," says Martha.
>
> – socio-emotional group, TN

Another aspect to maintaining normality is to hang onto the aspirations and goals one had prior to getting cancer.  Diane asks the group what they truly want to be doing with their lives:

> "How about the rest of you? If you could do anything you wanted right now what would it be?" asks Diane. Martha shakes her head. "I've already got all I want. I don't need anything else." "I'd become a graphic designer, you know, for the web," says Antonia looking upward running her hands through her hair. "Could you go to Tennessee Tech for that?" asks Diane. "Yeah they offer those classes," says Antonia. "How long would it take you?" says Diane. "Probably four years part-time," she groans, "but it would be too expensive."
>
> – socio-emotional group, TN

> “One of things I really want to do is get back into music," says Gerald. "Aren't you a singer or didn't you used to sing?" I ask. "I used to have a band at one time. I also owned a kareoke bar, too. Did you know that kareoke started in the Philippines?" "What does the word mean in Filipino?" asks Diane. "Oh the guy who invented it called it sing-along. The Japanese are the ones who named it kareoke," says Gerson. "I hear now they have virtual kareoke now," says Toni. "You mean you can put on those big goggles and just sing to yourself?" says Diane. "I guess so," says Antonia. "What I want to do in the Philippines is get a bunch of recording equipment from here and bring it over there with me. I'd like to open my own recording studio...”
>
> – socio-emotional group, TN

> "I've always wanted to go back and finish my degree. I'm an R.N. but I'm not a B.S.N. I think I already have all the core classes except for math. I just hate math. I'm fine with addition, subtraction, you stuff you need to balance your checkbook. Any kind of algebra doesn't make any sense to me,' says Bianca. "I also love history. American history and I'd take as many history classes as I could. Sometimes I take a book with me to lunch because you never know if you'll have someone to eat with. I was reading a history book and someone said, 'You're trying to study?' I said that this is for pleasure," says Bianca.
>
> – socio-emotional group, TN

Sometimes cancer patients talked about just wanting to move beyond their cancer treatments so that they can enjoy other aspects of their lives:

> I counted about 60 chemos in total." "How many more do you have this round?" asks Diane. "I have two more, but I don't know the dates. I just know they should be done in March. It's been three years since I've been able to have a birthday party for Jacob. I was reading his baby book and I had written in it no party this year, mommy's sick for three years straight." "When's his birthday?" says Diane. "March 31st," answers Martha. "So you could be all done in time this year," says Diane with a big smile. "Yes, I would just love that...”
>
> – socio-emotional group, TN

> "You know how you were talking about quality of life?" Gayle says to me. I nod my head. [When I first introduced myself to the group, I told them I was interested in studying the quality of life among cancer patients and survivors.] "I think that having a quality of life is real important. I'm young. I'm only 52. I mean I think 70 is young. If I survive this cancer, I still have a good twenty years to do something. I still want to have a career. I'm

> really interested in working on the environment, saving the trees and the beaches around here."
>
> – socio-emotional group, FL

Norm: One Should Try to Stay Involved

Perhaps because members at times become reliant upon others for their assistance, they often take the initiative when an opportunity arises to reciprocate. They also reach out to those whom they feel they can be of some use whether for informational or instrumental purposes. During group, members might solicit help from each other or report acts that they have performed for other people. These acts included both cancer and non-cancer related help. Caroline, for example, had developed an ovarian cancer awareness guide at her own expense and asked for help distributing her cards to various businesses around town:

> "Caroline, I wanted to tell you that I found a couple of new places to drop off those cards [ovarian cancer awareness cards that list the symptoms on one side and necessary tests on the other] like Edgewater and Deland. It so funny I managed to give [the cards] where I least expected it," says Gayle eager to talk with Caroline. "I have had so little energy I haven't gotten out anywhere," Caroline says with a hand atop her head. "Will you take some more?" she says eagerly to Gayle. "Sure, I suppose so, but I don't want to take the last remaining ones you have," replies Gayle. "I'll send Tim [her husband] back out to the car to get the extras from my flowered bag," says Caroline.
>
> – socio-emotional group, FL

Gayle assists Caroline in the distribution of her educational materials even though Gayle has a different kind of cancer. Gayle appears pleased that she was able to distribute more ovarian cancer awareness cards than she expected. When an out-of-town doctoral student needs respondents for his survey, Eddie encourages his group to participate:

> "There's a doctoral student in Greensboro who asked me to ask you all if you would fill out some forms for him. He's looking at spirituality and family support. I filled one out and it took no time at all. There's nothing threatening in there. I encourage each of you to

> do it. He needs them by the end of this month.” A member asks if the student plans to provide any feedback on his findings. "Well, I'm sure he’ll do something,"replies Eddie.
>
> – informational group, TN

Fellow member Patsy urges Jeff to volunteer at the hospital where most of their fellow group members have received their care. She believes that Jeff has much to contribute to other people with cancer:

> "With your personality, you would make such an incredible volunteer. Have you thought about checking with any of the area hospitals?" asks Patsy. "I have, yes," says Jeff. "At [the hospital] they have a former cancer patient who goes around giving patients manicures," someone says. "The woman there, uh, Delia, uh, I can't quite remember her last name but she is an amazing person," says Margaret. [Delia is the patient care coordinator at the hospital.] "They even bring pets up to the floors. It's just incredible." "You could push around the little coffee cart," continues Patsy. "Oh I think it would be great for me. I just have to be careful. I can't do certain things like bend down," says Jeff.
>
> – socio-emotional group, TN

Bianca believes she may be of some help to researchers interested in studying her type of cancer:

> Diane enters, waves, and hands Bianca an article. "Here, I got this off the Internet for you. It talks about the fact that they now think non-Hodgkin's lymphoma may actually be two different cancers." Bianca looks the article over and says, "You know it's funny that you just handed me this. I was just at the dermatologist the other day and he had to remove a basal cell skin cancer from me. I didn't think anything about it until I heard that some researchers in Denmark were investigating the link between skin cancer and lymphoma. They [the researchers] had their three addresses on there, so I thought, what the heck? I'll just write them and tell them about my situation. Who knows," says Bianca shrugging her shoulders. "I'm sure they are looking for participants. You could be a great help to them," says Diane encouragingly.
>
> – socio-emotional group, TN

Keith offers his skills to assist Bob’s daughter in her fund-raising efforts:

> "I've got great kids. I couldn't ask for any better except the one's a Democrat. I meant to tell you all that my daughter has started a foundation to raise money for pancreatic cancer research. She works in advertising and has already lined up these superstars for a benefit. She even got Radio City Music Hall to donate its space and time to host a benefit. The doctor told me that at best I had another four or five years to live and that just pissed her off. She decided to do something about it." "Please tell her that I am a film editor and if she needs anyone to edit commercials, I'd be happy to do it," offers Kevin. "Thanks, Kevin. Do you have a card? That's right I've got it at the office," says Jeff.
>
> – socio-emotional group, TN

The above three examples demonstrate instances where cancer patients have something particular to them that they can offer to others. Keith devotes a substantial part of his summer to running a camp for children with cancer. Without his prompting, members demonstrate interest in helping out the camp:

> "Karrie, when you go pick me up one of those applications too, would you?" says Bob. "Can you just come for a week?" asks Karrie. "Sure. You can come for one, two or the entire three weeks," says Keith. "Can you just come in the evenings and on the weekends?" asks Bob. "I think that would be too hard to do. I think it would be more disruptive for the kids," says Keith...."I want to help out Keith, but after being sick and missing so much work, I'm not sure if I can do it. They have been so generous with me about taking time off. They've even doubled my salary," says Bob.
>
> – socio-emotional group, TN

Cancer support groups stress the importance of maintaining a positive outlook, which helps to convince other members that their fate is not already predetermined. The norm that one should try to think optimistically encourages members to look for the positive in the things that healthy people ordinarily overlook. The belief that one will survive one’s cancer is reinforced by the norms of maintaining a normal existence and staying involved. By moving on with the usual routine of their lives, cancer can be reconceptualized as a temporary state and not a permanent one.

### Belief: It Is Important to Listen to Your Body

Norm: One Should Re-organize One's Priorities

The ideological belief in the importance of listening to your body also constitutes a behavioral norm for the support groups. Members describe how their respective cancer experiences have helped them re-prioritize and let otherwise unimportant things go in order to take care of themselves. Where the importance of work would have been at the top of Bill's priorities at an earlier time in his life, Bill's illness has forced him to put himself first:

> "He's so mellow about everything," Kate (wife) says. "I stopped working a few months ago," Bill (patient) explains. "That's definitely a big part of why he's mellow. He also sleeps until 11:30 in the morning and takes long naps in the afternoon," Kate adds. Betsy asks something about who takes care of their kids. "I do everything," Kate says making a sweeping motion with both arms.
>
> – socio-emotional group, FL

Bill not only has stopped working, but he has also stopped performing any household or child-related duties to get the rest he needs.

Paulette's husband fell seriously ill with cancer just before she herself was diagnosed with breast cancer. Up to that point, she had been the exclusive caretaker of her husband and had become exhausted in the process:

> "I had my mastectomy back in January that same time my husband was so ill. I recall that [my husband] also had major surgery around that same time. I remember that the doctor told me that he was going to release me on Monday and I said no way. I said, 'I have an extremely ill husband at home and I haven't slept through the night in four years.' I told him to figure out a way to keep me in the hospital until that Wednesday. And you know what? He did. Not only that, but nobody bothered me all Tuesday night. You how the nurses usually come in and draw your blood and all that? For some reason they didn't."
>
> – socio-emotional group, TN

Bill and Paulette need others to give them a break from their daily responsibilities. Their health and well-being comes first at this time.

Andrea’s daughter offers to care for her mother during her mastectomy, but Andrea rejects her offer:

> "Andrea, who is going to help you out while you have your mastectomy?" "My daughter is supposed to be coming down next week to take care of her mother, but we'll see. I just want her to take care of her critters [children]. I think it will be more stressful for me to have her here. It's just easier if I take care of everything myself."
>
> – socio-emotional group, TN

Andrea finds being by herself during her surgery would be easier that having to cater to her daughter and her grandchildren. Nanette, who ordinarily relishes the time with grandchildren, cannot take the racket they create at her house:

> "My son, daughter-in-law and their kids were over for the football game (Titans) on Sunday. My daughter-in-law cooked the whole dinner and I just sat in my chair the whole time. But you after a while, the noise of little kids starts to get to you and I just couldn't take it any more. I knew that my daughter-in-law would never leave without the kitchen being immaculate, so I had to tell my son to go in there and help her to finish. I mean I've never done anything like that before, but I had to this time."
>
> – socio-emotional group, TN

Nanette’s need for quiet supercedes her need to be polite to her son and his wife.

Ann Marie also learns to be less self-conscious in asking for help from others now that she has been diagnosed with a recurrence:

> "Sounds to me like you're doing a much better job of asking for what you need this time around," says Felice. "Yeah, I think so. People have been so generous," says Ann Marie.
>
> – socio-emotional group, TN

Jan, who works as a surgical nurse, talks about her colleagues’ treatment of her while she undergoes treatment for breast cancer:

> “I work around all these medical people who keep saying, ‘You can do it! Hang in there! Be strong!’ I mean I know what they are trying to do. They want me to persevere and fight it, but I just couldn’t [during chemotherapy]. I just had to take a rest. My body was crying out for a rest that I wasn’t giving it. You need to give yourself a break and give in. It’s only temporary.”
>
> – socio-emotional group, TN

Jan is simply too exhausted to put on the front of stoicism and endurance for the sake of her co-workers. She protects herself against outsiders’ sanctions by arguing that her “rest”, though necessary, would be for a short period of time. She also knows that the placement of her Christmas decorations really do not matter like they once did:

> "My sister came to stay with me and she put up all my Christmas decorations. She said, 'I don't know if this is where you want 'em, but they're up.' I didn't care. Usually I'm real anal about stuff like the yard, but now I don't care,” says Jan.
>
> – socio-emotional group, TN

Gerald believes the symptoms he has been experiencing mean he has relapsed. He makes plans to return to his native country regardless of what his wife thinks:

> "Gerald, what are you going to do about telling Carla?" says Diane. "Especially since you've made up you're mind about moving back home." "I don't really know. I hope that she wants to go with me," he says with a smile. "Didn't she used to come Monday nights to the friends and family group upstairs?" "That's right. She still goes," he nods.
>
> – socio-emotional group, TN

Sometimes not just activities or responsibilities get re-prioritized in the wake of cancer, but so do people like Gerald’s wife above or Mary Pat’s daughter below:

> "Maybe you need her to tuck you in," suggest Jeanne. "Yeah, right. My daughter got up the other morning and made me breakfast in bed. That was a real shocker that's for sure," says Mary Pat. "See, she needs to give you something back for all the things you do for her," says Ann Marie. "I suppose so, but I like making breakfast for her in the morning because I really like to eat breakfast." "Maybe you should let her do for you instead of you keeping yourself up and not getting enough rest," continues Ann Marie. "That's the other thing about being tired all the time. I want to be awake when she goes to bed to make sure that she goes to bed," says Mary Pat. "Patty, you have got to let that go," urges Ann Marie. "She's thirteen, she can put herself to bed." "I know but she'll stay up until midnight if I'm not awake," says Mary Pat defensively. "When my daughters were younger, they thought they wanted to stay up until all hours. I said fine. Stay up as late as you want, but just know that you have to be up at 6:00 in the morning, no matter what. They wound up going to bed at their usual time because that was what their bodies were in the habit of doing," says Patryce.
>
> – socio-emotional group, TN

Mary Pat fights letting her duties as a mother slide for the sake of getting enough rest. Ann Marie and Patryce attempt to persuade her that putting her teenage daughter to bed or making her own breakfast can slide.

The ideological belief that it is important to listen to one’s body has important implications for healing as quickly and as effectively as possible. The norm of reprioritizing and letting things go upholds this belief by urging members to put themselves and their health first as to avoid stress and to get rest in order to get better. Although the proceeding belief in thinking positively encourages members to maintain their normality by going about their lives as usual, this belief allows members to take breaks and slow down when they need to. This belief justifies “giving in” and allowing oneself a break from fighting cancer (or even annoying relatives) without feeling guilty.

### Belief: Cancer Support Groups Offer Safe Haven

Cancer support groups members clearly demonstrate a need to have a place where they can express themselves freely and openly without fear of being misunderstood or repelled. In the support group format, members share their own concerns and permit others to do the same.

The care they offer is not limited to the demands of one’s cancer, but extends to all aspects of a person’s life. Cancer support groups promote the belief that they provide a safe haven for those who need to vent, to discuss threatening aspects of their condition, to share successes, and to provide answers. Subsequently, the emotion, cognitive, and behavioral norms described here flow from this belief.

Norm: Members Should Make Each Other Feel Good

Group members adhered to an emotion norm of offering positive affective support. This could take many forms, such as compliments, reassurance, just being there to listen and gratitude. Elizabeth’s comments address the inappropriateness of other people’s emotional reactions to her disclosure of cancer:

> “Don’t you love people’s reaction when you tell them you have cancer?!” says Elizabeth becoming quite animated herself. “They say, ‘Oh my god, cancer?’” Elizabeth recoils in mock horror to make her point. “They act so shocked and then you never hear from them again. It’s the people who you don’t know as well who act really concerned.”
>
> – socio-emotional group, FL

Close friends, not acquaintances, should be ones who can be depended upon to provide sympathy and emotional support rather than horror and withdrawal. This kind of reaction reinforces why support groups are necessary.

For example, Gayle may be undergoing a particularly rigorous time in her treatment, nonetheless Paulette still compliments her fellow group member’s appearance:

> Paulette leans over to grabbing her on the arm and says to the group, "Can you believe how good she looks? She's just had her second surgery this summer and she's going through chemo. You look great,"gushes Paulette. I have to agree with her -- Gayle does look good. "I feel a little tired but other than that I feel pretty good," adds Gayle beaming.
>
> – socio-emotional group, FL

Gayle appears to feel genuinely touched by Paulette’s kind words.

Victoria perceives that the intensity of her anger about her illness exceeds the normative expectation for the situation, making her sound crazy when compared to the rest of the group:

> "I'm supposed to see the oncologist this week and decide what to do. [She's just been diagnosed with breast cancer.] I've read that book by Bernie Siegel and I am trying to do as he says. I can't wait to get over this shitty anger [about having cancer]. I guess I sound really crazy to all of you, huh?" [smiling with her hand in front of her mouth and her head cocked]," says Victoria, diagnosed with breast cancer...."I'm from a holistic family, too, so I grew up like that. You're trying to treat your mind and your body. I understand that. It's about total wellness," says Ann Marie.
>
> – socio-emotional group, TN

Ann Marie appears to recognize Victoria's need for positive emotional support and reassurance during the highly stressful time of deciding her course of treatment.

Robert describes how the caring and comradery offered by the support groups comforted him:

> Robert goes on to answer his own question, "That's why these support groups are so great. You don't get alone [sic] or isolated. I think the fear of dying is never real [when] someone is listening to you, responding to you. [While in the group], nobody could have a fear about dying. You might have a thought about dying, but you won't have that fear, the emotional side. I think [the group] almost totally eliminates it. So I am always looking to make sure I don't get too isolated and alone."
>
> – socio-emotional group, FL

Gayle seems pleasantly surprised by the fact that she has not completely fallen apart emotionally; however, she prepared herself by joining to a support group just in case:

> In reading the exchanges in an on-line chat room, Gayle had been frightened by others' experiences with her same type of cancer. "....People type because they are scared. I said that's why I came to a support group to start with, because I thought, 'Oh, cancer is so bad. Everybody says it is. I'm just going to fall apart...I thought I was going to be like everybody else. Am I denying this or suddenly [am I] going to wake up one week and go, ahhhhh! You know? You think you're going to feel so bad and you're going to be frightened, weeping, and all this stuff that people say you have with cancer. I just haven't felt that bad during my therapy. I didn't feel bad at any time. But I have, you know, a

> deadly disease that could turn around and I could be dead in a year. [She laughs.] Really, just dead in a year."
>
> – socio-emotional group, FL

Gayle's statement underscores the emotional norm of profound emotional distress for persons diagnosed with cancer. She expects to be emotionally distressed, a common and expected reaction to having cancer, and to her surprise she finds herself feeling better than she anticipated. Although Gayle's positive experience clearly violates the emotional norm for the group, the group takes no action to sanction her violation, implying positive group acceptance of people's feelings.

The groups themselves could transform the outlook of new members even after one week's time, as in the case of John:

> "Just in one week I have seen a huge difference in my family. Just one week since first coming to [the support group organization] and we already look forward to coming on Thursday nights. And my wife wasn't even in a group last week. She was in doing a customized personal plan with Fern. This past week we've already begun to communicate so much better with each other. It's like a total transformation. Instead of throwing daggers at one another like, 'Hey, I don't like what you did,' [scrunches face and folds arm to show anger] we have begun to sit down and talk about our feelings, which we have not been able to do since I got cancer...." says John.
>
> – socio-emotional group, TN

Eddie, the prostate support group lay facilitator, thanks all the family members who accompany the male members to the prostate support group meetings:

> "I want to thank those of you who participated in the student's study last month. He sent me a copy of his results and you know what he found? That having family with you is an incredibly important part of support groups. We appreciate all the women who are here tonight and at every group meeting. We encourage you to bring family members with you. We get together to find out how we can keep ourselves doing better..." says Eddie.
>
> – informational group, TN

Members of one particular group go as far as organizing a surprise baby shower for their professional facilitator to express their gratitude. They choose to surprise her during the regular meeting time and I make the following observation:

> The Monday Wellness group decided about a month ago that they would plan a surprise baby shower for their facilitator Sarah during tonight's meeting. Unbeknownst to me before tonight, the members had held a planning meeting to coordinate their efforts for this evening....On two different occasions where Sarah momentarily stepped out of the group, Jean reminded everyone to bring a gift and a food item for April 24th. I arrive this evening about 5:10pm with my brownies and modest gift in tow. I knew in part that I would feel terribly uncomfortable attending the meeting if I did not participate in the shower....The receptionist sees me with my arms full and hurries to open the door for me. "What have you brought for me tonight?" she asks jokingly. Felice turns and spies my plate of brownies and says, "Don't worry, Sarah won't be here until right before group starts."
>
> – socio-emotional group, TN

Members have brought an abundance of food and gifts to celebrate. Sarah, the facilitator, is taken by complete surprise:

> Sarah looks up and offers a weak smile. As her husband enters the room, her smile turns to semi-horror, "What are you doing? I thought you were just going to drop me off?" "Sarah! C'mon! Did you not notice all the gifts gathered behind you? Or all the food in the kitchen?" says Fern.
>
> – socio-emotional group, TN

Despite the fact that Sarah gets paid to facilitate groups at this cancer support group organization, members still want to demonstrate their affection and thanks for her guidance through their celebration.

Similarly, the positive outlook of one emotion focused support group even changed the way members saw how the group functioned:

> "We're almost a laughter group [referring to the Friday afternoon laughter groups offered at the support group organization] rather than a wellness group," says Sarah to me. "You have to laugh at this stuff, otherwise it's intolerable," says Patsy.
>
> – socio-emotional group, TN

These exchanges show how the positive feeling rule of making others feel good applied to oneself, to a fellow member, to family member participants, to new members, to the facilitator, and to the perception of the group itself. Where such positive sentiments may be freely exchanged in group, outsiders may not react in the same expected way as those who participate in the groups.

### Norm: One Should Expect to Receive Sympathy and Concern From Group Members

Another emotion norm of the groups was to express worry and concern about each other. Geoff arrives at group late, so Mary Pat recounts for him her recent hospitalization:

> "You missed it earlier, my whining that is," replies Mary Pat. "You came in late and missed Mary Pat talking about her hospital stay," Sarah informs him. Geoff looks aghast. "You were just in the hospital? For what?" "I spiked a fever and with this wound they plunked me back in the hospital to get antibiotics for five days, " says Mary Pat angrily. "What did they give you?" asks Geoff. She runs through her list of medications and when she comes to Vancomycin he says, "Oh that stuff makes you feel so good," "Oh it does," Mary Pat replies arching her eyebrows implying a little too good.
>
> – socio-emotional group, TN

Geoff's visceral reaction to Mary Pat's news conveys worry about her well-being. Geoff shows concern for Ann Marie's feelings over having revealed too much information about her personal life to the rest of the group:

> Ann Marie limps slowly to an overstuffed chair across the room while Keith takes my spot on the loveseat. "Ann Marie, I told them that you and Keith were together," says Geoff sounding embarrassed. Anne looks completely exhausted. "Oh, I don't care about that," she replies. "Well, I told them something else that I probably shouldn't have repeated," says Geoff smiling. "What's that?" says Ann Marie looking concerned. "I didn't want you to think I was talking behind your back in case you heard it from someone else. I told them that you said the sex with Keith is great, but not since the surgery," says Geoff breaking into hysterics again, slapping his cheeks and covering his face with his hands. "You told them what?!" says Ann Marie laughing. She and Keith

> both are completely flushed with embarrassment. "I told everyone that any man who waits on a woman to get her hair done..." adds Bob with his voice trailing off.
>
> – socio-emotional group, TN

Patricia feels self-conscious that she may have brought her fellow group members down by changing the tone of the discussion:

> “So I am sorry to have brought up such a sad story and bring everyone else down,” says Patricia apologetically. “I know that we laugh a lot in this group, but I want you to feel comfortable talking about difficult issues in here. That’s what we’re here for,” says Sarah, the professional facilitator.
>
> – socio-emotional group, TN

Sarah allays Patricia’s worry over sharing her depressing story by reminding her that one of purposes of support groups is the freedom of emotional expression without fear of sanction. Expressions of concern also extended into other parts of members’ lives not having to do with cancer:

> She reaches into her purse and pulls out a couple of photographs. "I've got some pictures of our miracle baby for everyone to see. I know a lot of you in here were praying for him and I thought you'd like to see what he looks like now. This is my sister's grandchild whom we thought wasn't going to make it. He had to have heart surgery right after he was born," says Patsy. "Is that the older brother next to him?" asks the other Mary Pat with pictures in hand. "Yeah. The baby already weighs 15lbs and his brother weighs 30lbs," replies Patty. The pictures move around the group and we all coo over them.
>
> – socio-emotional group, TN

The emotional norm of expressing concern still applies even when talking about seemingly ridiculous topics. Bob should have expressed sympathy or concern upon seeing Patryce’s distress, regardless of the source of that distress (in her case, a dead cat). In other words, Patryce’s upset should serve as a signal for how he should have expressed himself more appropriately:

> “We thought the cat had a urinary tract infection that was causing him to be tired, but the blood work came back as feline AIDS. We had to put the cat down for fear of infecting any of our cats,” says Patryce. “Oh yeah, feline AIDS is real contagious,” says Mary Pat seriously. “That’s the funniest thing I’ve ever heard! Isn’t that what tails are for? Swinging them into the grave?” says Bob. “Bob, she’s saying that the dead cat in the freezer [because the frozen ground prevents its burial] is bothering her and that’s why she mentioned it,” says Patsy. “I wouldn’t have mentioned it otherwise,” says Patryce. “Oh, you’re serious? I didn’t mean to offend you,” says Bob.
>
> – socio-emotional group, TN

While the women in the room seemed to be offering sympathetic comments on Patryce’s behalf even when the subject seems to be relatively unimportant, Bob thought her dead cat was a joke. Perhaps in other circumstances, Bob’s expressive behavior would have reflected conventional expression norms. But here in this example, one can see how patients in support groups have developed new norms about how one should feel or express themselves, and get exasperated when others violate their expectations

### <u>Norm: Members Should Feel Free to Vent and Complain Freely About Concerns, Annoyances, and Fears</u>

Members took the opportunity to vent their frustration and complain about the more demanding aspects of having cancer, another emotion norm found in the groups. Members often talk openly about chemotherapy as being particularly rigorous:

> “Chemo sucks, y'all. The doctor prescribed Compazine for me to deal with the nausea. I think I've told you all that I'm a recovering drug addict and I don't take anything unless I'm absolutely desperate. I wound up taking it and I couldn't keep my eyes open at all. I had all of these friends coming by the next day and I was really looking forward to having them there. I love to talk and I couldn't," says Julie.
>
> – socio-emotional group, TN

Chemotherapy interferes with Julie’s desire to function normally. Caroline apparently has been feeling particularly ill the past couple of months, which is also compounded by the effects her chemotherapy has had on her:

> "I've been so addled lately. I can't seem to remember much. All this chemo has fried my brain. I've already had a lot of nerve damage in my arms and legs, so there isn't much more that they can give me. Gayle what are you taking?" "I'm on Taxol right now," she replies. "I'm still on Tomoxifen," says Caroline.
>
> – socio-emotional group, FL

Patsy could not keep up with the demands of her teaching job and the demands of cancer simultaneously. Studies have proven the powerful effects chemotherapy has on the brain, as Bob discusses below:

> "I feel like I am losing my mind. You know how we all have memories of the absent-minded teacher? I'm afraid that if I kept teaching that I would have wound up like that with kids making fun of me. Could this just be menopause?" asks Patsy hopefully. "I basically have no memory of my childhood left. I also had a mild stroke that impaired my memory and then I had the chemo on top of that," says Keith. "You remember that Wall Street Journal article I was telling you about. It was a study done by the American Cancer Society that documented the memory loss associated with chemotherapy," says Bob. "Is there any chance it will come back?" questions Patsy with a laugh. "No, the Wall Street Journal article said clearly that your memory would not return," says Bob. "I see Mary Pat writing on her arm, so I know I'm not alone with this," says Patsy defensively. "I know I lost IQ points that I'll never get back. I was so worried that I might forget something for this evening."
>
> – socio-emotional group, TN

Chemotherapy impacts physical functioning as well. Martin still finds himself wiped out from his last treatment:

> "I had my last chemo two weeks ago and I still can barely do anything. I got up early this morning all ready to go shopping for my sister's wedding and I had to change the tire on my mother's car. That did it. I had to go back inside and rest after that," says Martin. "Don't you have your sister's wedding this weekend?" asks Diane, the facilitator. "Yeah, why do you think I went out shopping all day?" says Martin with a snort.
>
> – socio-emotional group, TN

> "I think even my wife forgets that I have cancer. She asks me what I do all day long. Today I did a load of laundry and some dishes and that was about it. I feel so useless most of the time. My five year old gets home about 12:30pm and about 2:00 we both

> take a nap.  My wife and my other daughter get home about 2:30 and they're fired up ready to go," says John.
>
> – socio-emotional group, TN

Nanette describes the emotional conflict she experiences as the result of her contradictory roles as both a health care provider and a patient:

> “I am a nurse anesthesiologist and I see iv’s all day long and even I couldn’t bear the sight of my own iv.  Ugh, the color of the chemo hanging there in the bag above me [she physically shudders]. I could feel a sunburst in my port as that stuff dripped into me.”
>
> – socio-emotional group, TN

As a nurse she should feel undisturbed by the presence of iv drips and chemotherapy bags, but as a patient undergoing chemotherapy treatment, she feels disgusted.  As a member of a support group she can vent about her disgust, whereas from the perspective of a nurse her feelings would be perceived as deviant.

### <u>Norm: One Should Find One’s “Deviance” Regarding Your Appearance Accepted by Group Members</u>

Being able to look sick constitutes a behavioral norm that upholds the ideological principle of the support groups as a safe haven.  Group ideology dictates that participants not only will offer positive support for one’s emotional well-being, but also extend their support for those who appear and function like someone with a major illness.

Outside of the groups, cancer patients take steps to hide other aspects of their physical appearance that outsiders would find too shocking or upsetting:

> Patryce begins talking about her Halloween costume. "I'm dressing up as a surgeon this year." "With a really long knife?" asks Geoff. "I've got this Frankenstein head I'm going to put on. It's got this black hair sticking out every which way, good and creepy.  I've got these fake wounds I'm going to wear.  I can't paint them on my skin because my skin is too sensitive, but I can just glue them on." "Why don't you just take off the bandage and use your real wound? Why bother with the fake ones?" suggests Geoff jokingly. Everyone laughs hysterically. "Oh yeah, wouldn't the kids love that?" Patryce howls.
>
> – socio-emotional group, TN

Mary Pat accidentally lets her daughter see her mastectomy scar:

> Anything has got to look better than the stinking scar. My daughter finally saw it by the way. You know how I've been saying she's never asked to look at it? Well we were lingerie shopping the other day at Profitt's and tried on underwear together in the dressing room. Of course, she couldn't help but see my scar," says Mary Pat.
>
> – socio-emotional group, TN

Keeping up outward appearances has important ramifications for how other's will react to cancer patients and how cancer patients behave, themselves in public.

Alternatively, members report that they may be penalized by outsiders for their physical appearance and physical functioning when they appear seemingly too "healthy" as in Jack's case:

> "There was a point where I couldn't walk twenty feet without feeling like I had to crawl the rest of the way. I had a temporary handicap tag hanging from my truck and when I got out there was this little old woman staring at me. She said, 'You don't look handicapped to me,' and I said, 'well, I'm sorry to hear that, ma'am.' She said, 'How did you manage to steal that tag?' I said, 'I have bone cancer ma'am and I can't walk all that far.' By this time there were four or five people gathered around me and their mouths fell open when I got my walker out of the back," says Jack.
>
> – socio-emotional group, TN

Although Jack's cancer was serious enough to warrant a handicapped parking spot, his apparent mobility rendered him undeserving of special treatment in the eyes of strangers. He describes a similar incident while out shopping:

> My wife and I went to Sam's over the weekend to buy a color TV. The woman just stared at me with her mouth open and said, '*You* need help?' [his emphasis] I said that I have bone cancer and I am afraid that if I pick that TV up my arms will stretch three inches longer. We got this big strapping guy to put it in the back of our truck," says Jack. "How did you get it into the house?" asks Diane. "My wife came in, sat me down on the couch, and got my neighbor and another woman to carry it into the house," says Jack.
>
> – socio-emotional group, TN

Appearances can be deceptive even when one has a serious illness. How one appears outwardly does not necessarily correspond to how one feels physically. Outsiders expect persons with cancer to look the part. In other words, in order to be credible a cancer patient must both act and appear the part of someone with a major illness.

The following excerpts demonstrate members' awareness that their appearance (in this case, being bald) is embarrassing, and thus not normative:

> "I look like Aunt Jemima," says Edna, wearing a scarf to hide her hair loss. "And you look good, too," adds Sharon. "I'm going back to work next week. They told me even if I can only work one shift the whole week that they really want me back," says Edna.
>
> – informational group, TN

> I enter the room at 12:00pm and already a woman whom I have not yet met is in the midst of telling her story. She looks frail and pale sitting there in the oversized chair. She wears a large, floppy pink hat to hide her inch long hair. Mimi (facilitator), Mary, Alison, Julie listen quietly as this woman explains how she recently dealt with an infection in her abdomen. I can clearly feel the somber mood of the group stemming from the gravity of this woman's story. I gather that she was fairly ill over this past weekend (4th of July), which alarmed her mother vacationing with her. I get the sense that everyone (or almost everyone) knows this woman's, Debra's, experience thus far with breast cancer. "But look you've got some hair!" says Mimi. "Oh, I don't know about that", says Debra. "Take your hat off and show us," encourages Alison. Debra removes her hat gingerly. "Look at that! You've got a lot of hair. It looks great!" exclaims Alison. "It's just adorable, Debra," says Mimi in a loving tone of voice. "Yeah, at least it's something," says Debra with a smile, "Of course it's going to all fall out again when I start chemo." Debra pats her head and puts her hat back on.
>
> – socio-emotional group, TN

Where bald female members may need to take steps to alter their appearance for the sake of others, fellow members and facilitators try to "normalize" being bald through compliments and positive comments. Women in particular felt the need to mask their hair loss using wigs or bandanas so that their appearance would not disturb others. Nanette relays an exchange she had with her grandson while still in the hospital after her surgery:

> "I was afraid that my little grandsons wouldn't want to come see me [in the hospital] without my long hair," says Nanette. "The one said he didn't want to see me bald, but short hair was still okay. He said he'd still come see me if I wear a wig."
>
> – socio-emotional group, TN

Karrie has a similar reaction from her young nieces:

> "Oh I know! My nieces don't like it when I don't wear my wig. They tell me to put my hair back on. One of them was talking about dressing up for Halloween and she was telling each one if us, 'You can have the red wig, you can have the green wig, and Aunt Karrie, you can have the brown hair that sticks to your head.'"
>
> – socio-emotional group, TN

Presumably, Karrie and Nanette feel the need to mask their baldness so that they do not upset young children accustomed to seeing them with hair. Even when a child may not be personally bothered by their grandmother's or aunt's appearance in private, being in public may be a different matter. Karrie has begun to grow some hair back:

> "I am so excited," says Karrie. "Wait, I thought you were still undergoing chemo," says Mary Pat. "I am. I don't know why my hair is growing in, but it is," says Karrie. "Mine did that too," adds Jeanne. "I guess I won't question it. I'm just glad it's growing. I had my wig off in the car to show one of my nieces. When we came to a stop she asked me to put it on real quickly. I asked her if she was embarrassed and she said yes," says Karrie. "How old is she?" asks Jeanne. "She's only six," replies Karrie. "Little kids will tell you just like it is," adds Jeanne.
>
> – socio-emotional group, TN

The young niece seems embarrassed that anyone else would see her aunt bald, even in the relative privacy of her own car. Her immediate expression of embarrassment overrides any ability she might have to mask her true feelings for the sake of her aunt. Nanette and Karrie keep their wigs on so that others are not made uncomfortable. Seeing a bald woman can be a shocking sight because it is not normative. I note my own reaction seeing Caroline for the first time:

> In the two weeks since I last saw her, Caroline's hair seems to have grown some, giving her at least a half an inch of white fuzz on her head. She sports the same two pins I notice in the last group meeting: a small, blue feminist pin (blue is the color for ovarian cancer) and a big blue button that states, "I am a cancer survivor." Carol is definitely not into hiding her cancer. I find her hair is perhaps the most shocking aspect of her appearance....
>
> – socio-emotional group, FL

Baldness in a woman often signals to others that she has cancer, especially when her eyebrows are missing as well; however, fellow member Jeff tries put a positive spin on baldness for Ann Marie:

> “As far as the whole bald thing goes, I think women should just go completely bald, get some great earrings, and pencil in their eyebrows just like a 1930s or 40s starlet. I think women look just beautiful that way," says Jeff. "I got more sympathy when I was bald," says Ann Marie, "but my nephew still didn't let me win at cards. Sometimes when people were mean to me I wanted to yell, 'But I have cancer, you have to be nice to me." Ann Marie starts to laugh. "Of course, you want people to say no to you," adds Margaret knowingly.
>
> – socio-emotional group, TN

Outsiders feel sympathy when they see a bald woman because they assume she must be sick enough to undergo chemotherapy. However, as Nanette and Karrie show, sympathy may have its limits when cancer patients violate appearance norms in public.

These next examples show how the group tolerates looking and feeling sick where outsiders do not. Group members tend to be more considerate of hair loss among themselves than outsiders seem to be. They seem to bend over backwards to demonstrate their support for one’s new look:

> "Agnes, your hair is much shorter this week," says Diane entering the room. "I couldn't get anyone to shave my head, so I did it myself," replies Agnes. "You did a really good job. It looks really even," says Diane. "My hair was a mess last week, all falling out and shit. This is much better," says Agnes. "You have a really good head for having such short hair. I've wondered what I would look like if I shaved my head," says Diane. "Let's

> hope you never have to find out! My kids can't deal with the fact I have no hair. Me? I have no problem with it," says Agnes.
>
> – socio-emotional group, TN

Agnes's desire for comfort supercedes her kids' embarrassment over her appearance. Diane, the facilitator, compliments her decision demonstrating the acceptance of her deviance in appearance.

Within the safe space of the group, women cancer patients acknowledged that they could reconcile themselves to their baldness even if their family and friends could not:

> "I never wore a wig, so being bald for me wasn't that big a deal. I'm a surgical nurse and with the exception of two and a half months I was at work and I have to wear a hat for work," says Ann Marie.
>
> – socio-emotional group, TN

> "I bought a wig, but never wore it. My daughter had her coming out ball and I got all dressed up with the wig. I looked at myself and thought, this isn't me. I tossed it onto the floor and went anyway." [Margaret is the woman who spent $800 on a real hair wig and wore it once. She seems very socially active in Nashville.] It's incredible the people that you meet."
>
> – socio-emotional group, TN

Karrie seems to be comfortable enough in her baldness that she can be daring:

> "I work closely with these four guys who were making all these blond jokes to me last week. So I ripped off my wig and said," I TOLD you I wasn't a blond!!" says Karrie. "I mean I am completely bald on top and I cannot tell you how shocked I made those guys." Everyone absolutely howls at Karrie. [She seems to be very carefully groomed and the idea of her whipping off her wig seems incongruous with her presentation of self.]
>
> – socio-emotional group, TN

In other circumstances, a compliment would be flattering. However, cancer patients appear to protest when compliments are given without a true understanding of their condition:

> "You know what I hate? When people tell me, 'boy you look good. In fact I don't think I've ever seen you look so healthy. You really look so good.' I must hear that a zillion times, especially from people at church. Then they think you don't have cancer anymore. With me I used to be 287 lbs, so losing a hundred pounds makes a big difference on me. But imagine if I didn't have those hundred pounds to lose? I'd be in some sorry shape. I mean I'm down to my ideal weight for someone my size, but what a way to lose it!" says Jack. "Well, I think people are searching for something to say because they feel awkward. I mean it's better than hearing, 'boy, you just look awful today," says Diane. "Or you're looking a little green in the gills," says Andrea. "The truth is I may look fine, but how I feel changes from minute to minute. If you were to ask me, how are you feeling? I would say, right now I feel fine, but ask me again in a hour or two," says John.
>
> – socio-emotional group, TN

> "At the last Ducks Unlimited meeting I had a guy come up to me and say, "Schmidt, how did you lose all that weight?' I said, "Cancer." And then he said, "Naw, c'mon tell me really how you lost all that weight." I said, "Cancer." The guy said, "I don't want to lose weight that bad!'"
>
> – socio-emotional group, TN

Others may mean well when they offer kind words, but their intentions backfire when they lack an understanding about one's private experience. At times, even similar others can fail to understand the discrepancy between one's public self and one's private experience:

> "I've had to get up, get dressed, and go into work that takes energy." "You mean you actually put on clothes to go to work?!" jokes Bob. "Yes, yes, I meant that I didn't go in dressed looking like this. I had put on nice clothes and makeup." "Well, you look great," offers Rob. "OH MY GOD!" exclaims Mary Pat clutching her head. "I was just about to talk about that! I am so sick and f--- ," she stops herself. In a calmer tone she says, "I cannot tell you how sick I am of people telling me that. Everyone at work keeps telling me I look so good. I mean how bad did I look before? This IS the face of cancer! I may look good, but I feel like shit." "Hey, I've got the same disease you do, so that means I know what bad looks like and what good looks like by looking in my own mirror. I can say that you look good and you do," says Bob defensively. "People don't know what else to say sometimes," says Jeanne. "That's true. They probably mean it,' says Patryce. Mary Pat does not look convinced.
>
> – socio-emotional group, TN

Mary Pat's anger stems from the fact that even her fellow cancer patients may act inappropriately towards her when they fail to understand that appearances can be deceiving.

From an outsider's perspective, their objections to being complimented seem deviant. But from their perspective, the failure to understand their true feelings and actual physical condition seems inappropriate.

In these next examples, members appear to understand what constitutes "looking the part" of someone with a major illness. Obviously their understanding comes from their own personal experiences. Here cancer patients acknowledge how they can work to gain sympathy from the mainstream world:

> "I can act like an old lady when I want to," says Paulette. She stands in front of her seat trying to look meek while clutching herself. "My grandson told me my daughter does the same thing." This time Paulette stands and clutches her purse to her chest. "Maybe I can do like Carol and go without my wig," jokes Gayle.
>
> – socio-emotional group, FL

> "Going without a wig opens new kinds of possibilities for you," says Ann Marie. "Get a cane and then people will really feel sorry for you!" laughs Jeff. He shakes his cane at the group,"I've got an extra one at home if you need it!"
>
> – socio-emotional group, TN

> "For some reason, when I step into the grass he [his pug puppy] loves to bite at my pant leg. He's vicious about it, too. When he grabs on, he won't let go. I stand there and try to shake him off, and he just holds on tighter and growls louder." Jeff growls and shakes his head, looking surprisingly like a pug in his imitation. "I'm sure the neighbors think, 'Oh see that poor old man out there with a cane out being attacked by a dog." Jeff howls at himself.
>
> – socio-emotional group, TN

Looking feeble, using a cane, or going bald are commonly understood cues that someone is not functioning optimally. However, group members seem to understand that a real discrepancy can exist between how one feels and how one looks. Members can be sanctioned by outsiders for appearing too sick or for not appearing sick enough. The ability to extend appropriate emotional support for one's condition stems from the empathetic understanding that group members share.

Believing that support groups offer safe haven is crucial because cancer patients need a place where they can speak and act freely without fear of repercussions. The norms of making each other feel good through compliments, reassurance, gratitude and the like may seem even more sincere and flattering coming from someone who has shared the same experience. The norm of receiving sympathy and concern helps sustain the idea that groups care about what happens to each other, an essential part of perceiving groups as a safe haven. Likewise, being able to vent and complain freely allows members to blow off steam safely away from those who might be less understanding or tolerant. Even physical appearance deviations (e.g., looking sick) are tolerated and understood by the group. Participants abide by the norms to maintain the groups as a safe haven because they all share the need for a non-judgmental forum in which to express oneself.

### Conclusions

In this chapter, I have described procedural, behavioral, emotional and cognitive norms that emerge from the discussion among cancer support group participants. Procedural norms are the guidelines that shape the structure and function of both information- and emotion-focused support groups. Within those group structures, fellow group members hold themselves and others to particular normative standards that flow from the ideological beliefs created by the groups.

The cognitive norm of following conventional treatment flows directly from the ideological belief that it is important to follow conventional treatment. Similarly, the cognitive norm of taking charge of one’s illness stems from the belief that it is important to take charge. The importance of maintaining a positive outlook is upheld by three norms: one should try to think optimistically; one should try to live and behave normally; and, one should try to stay involved. The behavioral norm that one should re-organize one’s priorities stems from the ideological principle that it is important to listen to one’s body. The ideological belief that support groups offer safe haven rests on four principal norms: members should make each other feel good; one should expect to receive sympathy and concern from group members; members should feel free to vent and complain openly; and, one should find one’s deviance regarding appearance accepted.

These normative standards, unique to cancer support groups, both shape and constrain the feelings, thoughts, and behaviors that occur within the group setting.  The particular nature of the norms described here support my argument that cancer support groups are like subcultures by promoting their own unique outlook on the cancer experience.

Collectively, these normative examples show that participants can and do participate in the legitimatization and/or sanctioning of feelings, displays and thoughts of other members depending on the ideological principle invoked.  Fellow members are able to do so based on the empathetic understanding acquired through situational and experiential similarity, as will be demonstrated in the next chapter.  As seen here, cancer support groups in this study create their own normative standards based on their understandings and experiences acquired through dealing with rigors associated with their respective cancers.  Members uncertain of the normative guidelines for behaviors, feelings, and thoughts expressed concern for reactions that seemed over-reactive or under-reactive.  Groups generally abided by normative rules and occasionally helped reframe the inappropriate comments of others.  The following chapter will demonstrate how ideology and norms impact the coping assistance offered and received within the support group setting.

# CHAPTER V

# COPING ASSISTANCE

In the previous two chapters, I have discussed the primary ideological beliefs emergent from cancer support groups and the types of norms (procedural, behavioral, emotional, and cognitive) that uphold these ideological principles and shape the interactions within group meetings.  In this chapter, I will outline the coping and social support strategies used by cancer support group participants to manage the problems related to their illness and to bring their acting, feeling and thinking in line with the norms and ideology established by the group.  I will outline the commonly accepted conceptualizations of coping and social support in terms of Thoits's typology of coping assistance (1986) in order to capture the supportive (and non-supportive) transactions between members.

As argued in chapter one, social support provision has been typically conceptualized as one of three kinds of assistance: emotional, informational, or instrumental (House and Kahn, 1985; Thoits, 1985). Others can assist someone in need by providing emotional support through expressions of concern and kindness that contribute to the feeling of being loved and cherished. Informational support is the provision of information or advice that can help guide or clarify one's situation, and thus provide a new perspective on one's problem.  Instrumental support involves practical aid in the form of physical assistance, money, or material goods.

Thoits (1986) argues that the supportive functions provided by others mirror the coping strategies persons use to help themselves, and thus support may be meaningfully described as coping assistance.  Folkman and Lazarus's articulation of coping contains three essential features – the *change* of *actual* thoughts and actions of the stressed person in a *specific* situation (the authors' emphasis).  They view coping as a continuous process of appraisal in which persons modify their coping efforts based on shifting circumstances.  The unfolding of the coping process demonstrates how demands of stress can change from encounter to encounter, or, in the case of cancer, from one point in the illness to another (Folkman and Lazarus, 1986). As a result, persons employ a variety of coping strategies to keep pace with the ever-changing dynamic of stress.

Folkman and Lazarus distinguish between coping efforts directed at managing the problem causing the stress or directed at the emotional response to the problem itself (p.150, 1986). *Problem-focused* efforts address how the problem may be altered, understood, or contrasted with alternatives in order to reduce threat. *Emotion-focused* efforts address the emotional reaction that results from an upsetting event. Thoits demonstrates that these two coping strategies used by persons managing their own stress parallel the emotional and informational social support efforts used by others to offer assistance (p. 417, 1986). Within these two strategies, helpers may assist in managing stress behaviorally or cognitively by reinterpreting a threatening situation or decreasing distress related to the situation (Thoits, 1986).

According to Thoits, victims of life crises often search for empathetic understanding – a critical factor for the perception of effective coping assistance. Additionally my data show transactions where providers perceive situational or experiential similarity along a certain dimension and offer their support accordingly, whether solicited or unsolicited. In this way, my data support Thoits's hypothesis that empathetic understanding significantly contributes to the provision of effective coping assistance. This underscores the transactional nature of social support/coping assistance. Moreover, situationally similar others possess a clearer understanding of one's supportive needs and desires and are less susceptible to the anxiety induced by discussing cancer-related matters (Helgeson and Cohen, 1996). Similar others may be more apt to give the best coping assistance.

Thoits also argues that the perception of situational similarity should optimize the potential for helpers to offer the most appropriate coping assistance. Because cancer support groups are comprised of fellow sufferers, they bring an empathetic understanding to the group that can only be gained by having undergone the same or a similar experience. Where Francis (1997) argues that professional leaders such as therapists or counselors bring with them certain stock "definitions" for problems delimited by the boundaries of their professional training, I argue that fellow support groups members' own experiences as cancer patients likewise limits the kinds of definitions they may offer.  In this way, coping assistance offered within the cancer support groups that I observed appears to be limited by the ideological beliefs constructed by the group.

### Coping Assistance Illustrated

I will briefly illustrate each of the four functions of coping assistance outlined by Thoits's typology.   As mentioned above, both problem-focused and emotion-focused support may be framed cognitively or behaviorally and may be solicited or unsolicited by the distressed person.   Problem-focused support may be utilized when features of the environment are responsive to change (Folkman and Lazarus, 1986).  The most common coping assistance strategy I observed was behavioral problem-focused coping.  Behavioral problem-focused coping may characterized by "avoiding or manipulating the situation itself" (p. 418, Thoits, 1986). Requesting/receiving advice and clarifying information are problem-focused coping strategies that assist members to define the problem, generate solutions, consider the pros and cons, and choose a course of action (p.152, Folkman and Lazarus, 1986).  For example, May seems pleasantly surprised when she finds that other members know what to do about an annoying medicine side effect:

> "I've enjoyed listening to everyone else talk this evening. I did want to ask one thing. Does anyone else get cramps with [some name of medicine] or is it just me?" asks May. "You mean leg cramps?" asks Gerald. "Uh huh," says May. "Oh yeah, the kind that hit at one or two in the morning?" asks Gerald. "Exactly," replies May. "I get them and I have to bite my lower lip like this," he says making a face. "I have to get up out of bed and walk around to stretch out my legs," says May. "These are cramps you get as your body grows tired," says Diane. "Potassium. I used to get those and they come from a depletion of potassium. Eat a banana or drink some orange juice. In addition to all my conventional treatments, I did all the holistic stuff too which is why I know a lot about diet," says Jack. "Yeah, I have those things in my house for Andrew [her husband], but I don't like them myself.  Gee, I'm glad I asked that question!" says May sounding appreciative.
>
> – socio-emotional group, TN

Cognitive problem-focused support consists of reinterpreting circumstances so that they seem less stressful (Thoits, 1986). When the circumstances themselves cannot be altered, persons can re-evaluate the meaning of a potentially threatening situation so that it evokes more desirable feelings (Thoits, 1986). In the next example, Rob's doctor helps him reinterpret the aches and pains he has been experiencing:

> "I've been having some back pain lately. In my upper back and shoulders," he rolls his shoulders and rubs his back with one hand. "My doctor told me that I had a really extensive surgery and that the pain could radiate all the way up here. I did do a fairly extensive hike this weekend and so that could have something to do with it. I guess I'm just not in the physical condition I used to be in." [Rob is a big hunter and in hearing him speak I definitely get the impression that he's really physically active.]
>
> – socio-emotional group, TN

Others, such as Rob's doctor, can offer suggestions to assist him to think differently about a problem so that it appears less ominous or overwhelming.

Emotion-focused support, as the name implies, "is directed at regulating the emotional response to the problem" (p. 150, Folkman and Lazarus, 1986). Emotional responses may be managed cognitively or behaviorally to reduce further distress. Behavioral emotion-focused coping consists of functions that change the physiological symptoms that accompany emotional upset (Thoits, 1986). For example, groups can also offer spiritual assistance in the form of prayer to counteract a negative emotional state:

> "Eddie, I just wanted to make an announcement on behalf of James who had to leave early to get someone at the airport. I think I am saying something that he'd want everyone to know. His wife is facing breast cancer treatment and I believe had her surgery last Thursday," says Chip. "That's right. Not only does he have prostate cancer, but his wife also has breast cancer. Let's all of us keep them in our thoughts and prayers. Thank you all for coming and see you next month," Eddie says.
>
> – informational group, TN

I would argue, however, that with regard to this particular function of coping assistance, my data show the perceived availability or mere presence of a comforting individual also serves to alter physiological symptoms:

> “I don't know what I 'd do without Ted. We've been together 22 years and of course I've loved him all that time, but I really love him now. There has never been a moment where he's faltered. He's been by my side the whole time, never complained,” says Jeff of his partner.
>
> – socio-emotional group, TN

Cognitive emotion-focused coping focuses on minimizing emotional distress by altering one’s thinking about a situation when the situation itself cannot be changed. The meaning of a situation can be construed to be either a “realistic interpretation of cues or a distortion of reality” (p.151, Folkman and Lazarus, 1986). These are what Folkman and Lazarus call “cognitive maneuvers” that individuals engage in to restore their emotional equilibrium (1986). For example, Dale’s mother died earlier in the week. Agnes tries to relieve Dale’s upset by putting a positive spin on the means of her death:

> "Dale, I hear you got some bad news this week," says Diane leaning forward. "Oh yeah?" says Agnes looking up from her knitting at Dale. "Yes, I did," says Dale stammering. "My mother died yesterday. She just stopped breathing. It wasn't like..." makes a gagging noise like being choked. "She just died in her sleep," he says. "So she died peacefully," offers Diane. "The best way to go," says Agnes.
>
> – socio-emotional group, FL

I will show how the various coping assistance strategies are used by members to uphold and reinforce the ideological principles and norms of the group.

### It Is Important to Follow Conventional Treatment

The ideological principle of conventional treatment reflects a steadfast belief in the standard treatment regimen (e.g., surgery, chemotherapy, radiation) as the best means of beating cancer. Below Gayle and her fellow support group members uphold the belief in following conventional treatment by finding research that shows that the treatment works

> James says, “Every time I go to the doctor, they seem to come out with these cancer cures and their sample is like thirteen people! That’s why the empirical evidence has to be there before you can make a challenge.” “You can find almost any study to agree with whatever you say. You can find it if you look hard enough and sometime you don’t even have to look that hard. You can find something to match what you want to believe,” says Terry. “That’s what I always say. I find that whatever my doctor says, I can go and find a study that supports [his assertion]. I follow the doctor, I do! I go the medical library and find something that supports it. Whatever treatment I’m given, I’ve got studies to back it up,” says Gayle.
>
> – socio-emotional group, FL

Gayle demonstrates an extraordinary devotion to her doctor and his plan for treating her. In addition to upholding the norm for following conventional treatment, the discussion above seems to uphold yet another ideological principle – it is important to taking charge of one’s illness. However, the importance in taking responsibility for oneself by collecting information and research generally arises from the skepticism about the doctor’s opinion rather than wholehearted support in Gayle’s case.

Making decisions about how to treat one’s cancer prompts others who perceive situational similarity to speak up when Victoria questions conventional treatment. Patsy asks her if she has any children:

> "A five year old," Victoria says in a soft voice. "That's something you really want to consider when you choose your course of treatment. I was willing to do anything I needed to do in order to stay alive and my daughter is 24 years old," responds Patsy. Victoria seems to think about what Patsy has just said and stares down at the floor...
>
> – socio-emotional group, TN

Patsy appeals to Victoria as a mother to implore her to follow a standard course of treatment rather than deviating into the unpredictable world of alternative medicine. At the same time, Patsy seems to understand the intense emotional circumstances surrounding the decision about one's treatment, even when that decision conflicts with the ideology promoted by the group. She urges the group to back off Victoria:

> Patsy says to the rest of the group, "Let's try not to say too much right now. That happened to me, not here, but in another group I used to attend. I was absolutely scared out of my wits by the time I got to treatment." "I know we sound like we're really pro-chemo, but we support any decision you want to make," says Patsy. "Well, it's what you know," acknowledges Victoria. "It's that we look up to the medical profession like they are these god-like figures."
>
> – socio-emotional group, TN

Patsy seems to be suggesting that there is a more appropriate time to convince Victoria of the superiority of conventional treatment than now when she feels so emotionally vulnerable. Similarly, the group goes easy on Mary Pat's wavering about following through with surgery, offering only supportive empathetic comments:

> "How are you Mary Pat?" asks Sarah redirecting the flow of conversation. "Fine, fine. I am still undecided about my breast reconstruction surgery," says Mary Pat. "I've decided not to decide for a while. I just completely dread the idea of another surgery," she says slowly. "I understand that, Mary Pat. Boy, do I,' says Rob shaking his head. "I do too. I have to go in on Wednesday to get my third boob repaired," Jeanne says pointing to a bulge just below her right breast.
>
> – socio-emotional group, TN

Group members seem to be more sensitive to emotional distress around treatment decisions at certain times than others. Patricia's breast cancer was caught early enough that chemotherapy may be prescribed as an extra precaution. The group fails to realize that their casual conversation about their chemotherapy treatments scares Patricia:

> "I got served lunch when I was receiving treatment. I would eat this big, ol' tuna sandwich that was delicious," says Jeff. "Oh how could you do that? I had no appetite when I got chemo," says Ann Marie. "Neither did I. I had no desire to eat," says Bob. "Well for my cancer I wasn't getting chemo, I was getting [says name of drug] so I am sure that was the difference. I would stay in the hospital for seven days and get [the drug] for twenty-four hours straight," says Jeff. "I got chemo for six hours at a time," says Sam. "That's very unusual, though," says Ann Marie to Patricia. "Most people only get it for two hours. Mine was only an hour and a half." "Well the whole thing with me is that I can go either way. I don't have to have chemo except as a precaution," says Patricia seeming a little defensive.
>
> – socio-emotional group, TN

The belief in conventional medicine stems from members' perception that this treatment path offers the best hope for living a cancer-free life. While these quotes demonstrate the lengths to which members will go to adhere to this ideological principle, they also demonstrate the limitations of its enforcement. Although the group often acts quickly to reframe deviant beliefs to enforce ideological principles, emotional support comes first and foremost when members feel distressed or frightened. Thus, when the ideological principle of following conventional medicine is the focus of discussion, members offer primarily problem-focused cognitive assistance, followed by emotional support at times of vulnerability.

### It Is Important to Take Charge

If cancer patients wish to recover from their cancer or at least live with an improved quality of life, then they must take responsibility for their care and treatment. The support groups strongly enforce this ideological principle to ensure that fellow members have the best possible chances of outliving their cancer.

Forms of coping assistance that uphold the ideological principle of taking charge include advice and clarification sought by the members themselves, provided by fellow members, or provided by guest speakers, usually health care providers. Peter describes the difficulty in selecting the most appropriate treatment protocol for his melanoma:

> The conversation turns to the difficulty of knowing what to do once you are newly diagnosed with cancer. "I called MD Anderson, John Wayne, Jefferson, and Moffit [cancer centers] and they all had different protocols with different statistics. All these statistics made it so confusing. I mean how do you compare one against the other?" says Peter. "I kept telling you there are no guarantees! What do you expect? You've got cancer!" Elizabeth says angrily.
>
> – socio-emotional group, FL

Trying to select the best treatment path proves to be mind-boggling for the novice patient. His partner, Elizabeth, who accompanies him this evening draws further attention to an already stressful situation. By failing to be supportive in his efforts to cope, she also undermines his efforts to reinterpret his situation as less threatening (a negative cognitive problem-focused response).

Below, Patsy and Karrie chastise Mary Pat for not being better educated about the nature of her breast surgery, so that her missing breast may be reconstructed to match the other breast:

> "You had staples?" asks Patsy incredulously. "Yeah, how was I supposed to know what they'd use to stitch me up?" says Mary Pat defensively. "You ask!" says Patsy with Karrie nodding. "Why on earth would they have used staples on you?" says Patsy angrily. "I had no idea that's what they were going to use," says Mary Pat shrugging her shoulders. "They did that to me, too," says Bob. "They didn't bother me until it was time for them to pull the staples out. My kids wanted to see my scar and watched the doctor remove my staples. They thought it was cool," says Bob. "It's no wonder you have so much tightness and pain with your scar. Did they save any tissue from your surgery?" asks Patsy. "I don't know if they did nor not. Why would it make a difference?"says Mary Pat. "Because they can weigh the tissue after they cut it out and that way approximate your breast size," says Patsy.
>
> – socio-emotional group, TN

Patsy and Karrie have both had mastectomies and reconstruction, and thus perceive themselves to be in an appropriate position to give advice.

Likewise, Melanie comes to group this evening to solicit information from Bob:

> "I'm glad to see you here tonight, Bob, because I remember the last time I was here you had that bag attached to you," says Melanie to Bob. [Melanie has not been to group since I began coming in October. She has colon cancer and has been seriously ill] Bob looks a little perplexed at first and then says, "Yeah, that was months ago." "They are thinking about giving me one of those, but I wanted to find out from you how it went. I'm worried about the bag because I can't afford to lose any more weight," says Melanie. "I would pin that bag to my shirt so that I wouldn't get tangled in the tubing. I had to have it with me 24 hours because I was also receiving radiation 24 hours a day. It really wasn't bad," says Bob. "I am just so confused about what to do because I have one doctor telling me one thing and another doctor telling me something else," says Melanie. "I did lose 30 pounds, but I had a pretty major surgery and was in the hospital for months," says Bob.
>
> - socio-emotional group, TN

When the doctors provide conflicting information, Melanie looks to Bob's experience to help guide her decision-making. Patricia looks to Sam to provide similar assistance regarding breast reconstruction:

> Patricia sits on the couch opposite of Sam and me all curled up in a ball with her shoes off, clutching a pillow. "I'm really glad you're here," Patricia says to Sam. "You're the reason I came tonight. I really wanted to talk to you about your [breast reconstruction] surgery. My doctor told me that I'm not a candidate for self-reconstruction." "You mean you'll have to get an implant?" asks Sam. "Yeah, and I really do not like the idea of anything foreign in my body AT ALL," Patricia emphasizes. "I know what you mean. I guess you don't have enough fat around here to do it," Sam says making a sweeping gesture over her abdomen. "I didn't realize I had enough to do it, but turns out I had a little roll of fat they could use." "Yeah, I don't really understand why not," says Patricia. Sarah, the facilitator, overhears the conversation between the two of them, "Have you ever heard of a book [I miss the name of the title]? We have it here in the library, but it's usually checked out most of the time. Let me go check quickly to see if it's here. It's got a picture of every type of reconstruction there is."
>
> – socio-emotional group, TN

Patricia turns to Sam, a fellow breast cancer patient, to help her understand her doctor's decision to use a breast implant instead of her own breast tissue. Sarah, the facilitator, intervenes offering another avenue of assistance (in this case, a book of reconstruction photographs) to Patricia. These examples demonstrate that members perceive experiential similarity among specific group members and single them out for coping assistance.

Perceptions of experiential similarity can also prompt members to offer unsolicited coping assistance to those whom they feel can use their advice:

> “...I had a low white blood count from the chemo. The doctor wants me to take Neupagin [sp?], but I don't wanna take that stuff. I heard the side effects are terrible," says Agnes. "Neupagin? Oh, I've taken that. My arm was a little sore, but other than that, I had no problems whatsoever," offers Bianca. A new member, Jack adds, "I have taken Neupagin, too. I just had a little soreness from the shot, but other than that it was like injecting water." "Agnes, you'll be all right," says Bianca. "That's good to know,” says Agnes.
>
> – socio-emotional group, TN

Bianca and Jack’s own experiences with a drug intended to boost one’s white cell count encourage Agnes to follow her doctor’s advice. (Their encouragement also underscores the ideological belief in following conventional treatment as well.)

Ann Marie, a breast cancer patient and a nurse, gives Jeff information she perceives he needs to challenge his doctor’s decision:

> "I went to see my primary care doctor who told me that I didn't need hernia surgery after all," says Jeff. "Let's see your hernia, Jeff," says Jeanne. Jeff leans back in the chair and pulls his shirt taut across his belly. His hernia is quite pronounced and protrudes like a pregnancy. "It's my alien pregnancy," says Jeff. "And your doctor told you she wouldn't operate?" says Ann Marie, leaning forward to get a glimpse. "She said she would if it became, uh, strangulated?" says Jeff unsure of the word. "Strangulated is right. That's when part of your bowel dies," says Ann Marie. "My bowel might die?" says Jeff sounding shocked. "Sometimes part of the bowel protrudes with a hernia. That's what that is, Jeff," she says pointing at his belly. "This is my bowel?" says Jeff holding the hernia. "Yes, it's pressing right up against your abdominal wall. Sometimes the bowel gets strangulated by the hernia and the doctor has to go in and remove the dead bowel," continues Ann Marie. "I had that. The doctor took out about this much of my intestine," says Keith holding up a thumb.
>
> – socio-emotional group, TN

Fellow members tell Patsy that experiencing pain on a daily basis is an unreasonable way to live:

> "My scar is this huge indentation around the side of my body [she points from her breast bone under her arm to her back]. It seems as though the scar tissue has attached itself to my chest wall, making it feel so tight," says Patsy. "I've got the same thing, Patty. My skin hangs over where the scar is," says Mary Pat. "But you don't have the tightness," says Patsy. "No, I don't, but I worked pretty hard to regain the mobility in my right arm," says Mary Pat. "Patty, you've just got to get comfortable. That's the bottom line with having that surgery. You just can't continue to have pain like that," says Bob seriously. "I know it. I'm tired of it," says Patsy with a sigh.
>
> – socio-emotional group, Nashville

Mary Pat and Bob urge Patsy to be pro-active in dealing with the pain caused by her mastectomy scar and to undergo the necessary surgery that will relieve her tightness.

Professional supporters such as guest speakers or facilitators provide a particular kind of coping assistance to group members. Often their advice sounds highly clinical or technical in nature, usually because this is the sort of highly detailed information cancer that only someone with a health care background can provide. The informational groups in particular (prostate and breast cancer specific group) almost entirely consist of the search for and provision of professional advice (e.g., what to do) as well as clarification (e.g., understanding what to do). The following examples illustrate the provision of advice by medical professionals:

> “What has changed tremendously is the response of chemo when hormone therapy fails. This is where a group like this is great because I hope to get the word out. Most doctors don't know about chemo and part of it is our [the medical oncologists'] fault because we're publishing in medical oncology journals." The doctor removes his tie and continues, "It's like a self-fulfilling prophesy whereby the urologists sends the patient to the medical oncologist with six months to live and it's too late for chemo. The cycle is being broken by getting the urologist to send the patient earlier and earlier....If a urologist doesn't believe in chemo, he won't refer the patient to a medical oncologist. It's not a conspiracy, it's just a bias based on the literature they read. As the information gets out, chemo will have the maximum benefit in the early stage of disease. Funny if you're in oncology long enough, you'll hear that's it's unethical to treat prostate cancer with chemo

> that early. I heard the same thing with breast cancer 20 years ago. Hopefully in five or six years chemo will show some benefit for the early stages of disease. In a case where some has metastatic disease, it can only relieve symptoms."
>
> – informational group, TN

> If you have one family member with prostate cancer, you have a two-fold increase. If you have two or more family members, your risk becomes six fold. However, the number of men who actually have a hereditary component to their cancer is only 10%, meaning that 90% do not have a family history. The people who need to be screened early are African Americans with a family history of prostate cancer," says Dr. Lopez. "Ninety percent are sporadic cancers; in other words, these cancers came out of the blue. I am not down playing talking to sons and grandsons, but we need a better understanding of the factors that stimulate cancer in the other 90%. Basically you have the prostate developing and something happens to cause that cell line to become a cancer cell line..."
>
> – informational group, TN

Medical advice offered in the groups can often sound highly technical. Physician guest speakers appear to presuppose that cancer patients are well-informed enough about their own cancers to understand the medical jargon used.

Consistent with the ideological tenet of taking charge of one's treatment, cancer patients often *were* well informed enough about cancer that they could challenge the advice offered by a professional. Caroline offers the following observation about doctors' supposed intellectual advantage:

> "As an ex-teacher, I sat down and thought to myself. You know, I would teach a class of kids a year and some of them were very bright and some of them weren't very bright at all. They kept on going to school, college, med school. You always have the ones where were really bright and the ones who just barely get in. This is true with your doctors. You can go to Harvard or you can go to anyplace else, but there are always one or two guys down here who just barely got in. You can pass as well with an A as you can with a D, and [as a patient] you don't know which is which," says Caroline.
>
> – socio-emotional group, FL

Caroline’s commentary on the mediocrity in medicine (like any profession) offers some justification for why cancer patients should challenge their doctors.

Sharon is a nurse conducting tonight’s support group on a condition known as lymphedema that can arise when one’s lymph nodes have been removed. Jane, a group member, counters Sharon’s suggestion that more women should consent to a more conservative approach to lymph node removal known as sentinel node biopsy:

> “I assume everyone here has had their nodes removed," Sharon says looking around. "Well, I just had two nodes removed in my neck, but I did not have them removed any place else," says Cindy. "Oh, that's good," replies Sharon. "Have any of you heard about sentinel node biopsy? I am really surprised that more patients are asking to have that done instead," she adds. Sharon explains that rather than removing all the nodes particularly around the armpit, doctors can inject a dye into one node, see how far the dye travels, and just remove the affected nodes. Jane, a third woman who entered late, says, "I thought there was a decent amount of controversy about that. Doctors weren't sure whether they got all the cancerous nodes or not because sometimes the cancer may be undetectable in a lymph node," says Jane. "Hmmm, I guess so. I hadn't thought about that," says Sharon.
>
> – informational group, TN

It is the breast cancer survivor, Jane, who informs the health care professional, Sharon, about the serious limitations of the procedure she is recommending and not the other way around.

Tonight’s physician guest speaker discusses the fallibility of the diagnostic blood test used to detect prostate cancer, the PSA:

> "I think you're discussing an important issue because we put so much faith in the PSA," says the same man. "How much good are we doing by just watching the PSA drop?” “I would love to have patients with more measurable disease to make the comparison [against] the PSA. It's a better marker than most tumors have, but it's not great,” says Dr. Karl. "Can you use other tests besides the PSA?" asks the older African American man. "Name one. There have been comparisons of the PSA to the PAP, and the PSA always wins. It's more sensitive," replies the doctor. "The PAP wins sometimes, too," says the man.
>
> – informational group, TN

A member of the prostate cancer group contends that another kind of blood test for prostate cancer can be equally as sensitive in detecting prostate cancer.  His information disputes the argument set forth by the doctor.

When the physician guest speaker tries to downplay the dangers of Viagra, members reject his efforts:

> The doctor digresses into all the media hype around the few deaths related to Viagra.  He claims the media is simply trolling for stories by over-dramatizing these deaths related to a relatively safe drug...."Does it cause your blood pressure to go up?" asks a man about Viagra. "This is not a joke," cautions Dr. Frost," but it came out originally as a blood pressure drug and then the researchers found it [helped erectile dysfunction].”  Several others laugh. "In the clinical trials, the other men wouldn't give back the pills." "Are you saying that it's dangerous with diabetics" someone asks, referring to an earlier discussion. "Yes, Viagra can be dangerous, but cardio exercise in general can be dangerous in older men," says the doctor. "A speaker told us that it is was [dangerous] and that was just a year ago," challenges another man.
>
> – informational group, TN

In essence, the doctor suggests that taking Viagra is no more dangerous than physical exercise, a cognitive problem-focused reframing rejected by the group.  The members of the prostate support group search for clarification and question the doctor’s casual dismissal of Viagra’s lethal potential.

In a later support group meeting, another member of the prostate cancer group confronts the physician guest speaker about the shortcomings of the hormonal research being conducted:

> Jim asks, "Why aren't we seeing trials in prostate cancer using Herceptin that has clearly been shown to reduce hormone levels in women?" "For the most part we cure most people with prostate cancer.  Frankly, the treatment is so good that we rarely send patients to chemo," answers the doctor.  Jim says, sounding more agitated, "Why isn't the urological community looking at these other hormonal treatments.  We've heard so much about how well women with breast cancer are doing as a result of it. Robert Bazell, the medical correspondent for NBC news, just wrote a whole book about Herceptin."  The

> doctor doesn't seem to have anything new to add. "The treatments we have work for the most part. As part of my practice, we have a research team and I'll ask them," he says.
>
> – informational group, TN

In this case, the member seems to know more than the doctor, which seems to persuade the doctor to investigate further. By asking informed and challenging questions, group members actually role-model an appropriate problem-focused coping behavior for others in the group. Thus, coping assistance, here, is more indirectly offered through members' own examples of modeling rather than explicitly telling someone what he might do.

Other cognitive-emotion focused efforts include the participation of others in reappraising stressful situations so they seem more manageable, as in the case of Jeff's insurance coverage:

> "I just discovered my insurance packet unopened on my dining room table," says Patsy. "Whoops. I totally forgot that," says Jeff. "When was that thing due?" "October 15th," Patsy says. Jeff puts both hands over his mouth in shock. "I can't believe it. Is that the packet where you have decide what kind of insurance coverage you want for the next year?" he asks. "Well, I guess I'll just stay with COBRA. Oh well. I get insurance until I'm 65, but I probably won't live until then," Jeff half-heartedly jokes. "You say that now, but when you turn 66, you'll be saying damn, I wished I had done something about this earlier," retorts Keith.
>
> – socio-emotional group, TN

Keith rejects Jeff's pessimistic outlook. Consistent with the ideological belief that members need to take care of themselves, Keith's reinterpretation aims to motivate Jeff to take care of important matters like insurance coverage.

At times, outsiders served to exacerbate a stressful situation through their interpretation of events. Agnes does not appreciate her doctor's attempt at minimizing her diagnosis, conceivably as a means of reassuring her:

> “He told me I had 'garden variety' breast cancer. I ask what in the hell did he mean by garden variety? I got a copy of all my reports and read through everything. I went back to him and said, 'I don't see anything about garden variety in these papers.' I mean I'm not retarded. He later apologized for his remark. I guess he was having a bad day or something " Agnes says with a smile. "That article I gave Bianca had common cancer in the title. What's common about cancer? I'm sure no one with cancer believes what they have is common!" says Diane.
>
> – socio-emotional group, TN

Thus, much of the coping assistance involved in supporting the ideological principle of taking charge deals largely with the seeking or provision of advice and cognitive reframing of stressful circumstances. Similar others and professional experts could offer advice or clarification to assist in one’s own efforts to educate oneself in order to be as informed as possible. Unlike professional supporters, fellow members who perceived situational or experiential similarity offered unsolicited advice to specific whom they thought they could help. Well-informed members would reject advice when it conflicted with their own understanding of the situation, even when that advice came from a health professional.

### It is Important to Listen to One’s Body

As mentioned in the previous two chapters, the ideological principle of listening to one’s body encourages members to eat well, rest, and reduce stress in order to recover from the rigors of their illness and minimize uncomfortable side effects, relapse, or even dying. This principle is also upheld by the norm to re-prioritize and put one’s recovery process first. Support group members reporting dealing with the stress of cancer by removing themselves from the situation at least temporarily:

> "I remember they wanted me to have a colonoscopy right before I was supposed to take a trip to Florida with my mother and sister and I said no. It would have to wait until the week I got back. I mean what was the difference? The cancer was still going to be there a week later. We went down to Florida and golfed for a couple of days," says Antonia. "Did you worry while you were on your trip?" asks Diane. "A little bit. I had one bad day, but the rest of it I really enjoyed." "Remember what Dori did right before her

> mastectomy?" asks Diane of the group. "She went whitewater rafting the day before," she says answering her own question.
>
> – socio-emotional group, TN

> “When are you having your mastectomy?" asks Diane. "I am going to have that on the 20th. I need to go to Chicago before then to take care of some unfinished business. Ten days won't make much of a difference in the long run," says Agnes. "Just like Bianca!" says Diane turning to Bianca. "You went to Florida, right?" says Diane. "My husband, daughter, son-in-law and their two kids had planned this trip to Disney World. I got diagnosed on August 3rd and had my surgery about a month later," explains Bianca.”
>
> – socio-emotional group, TN

In the exchanges above, group members did not allow their cancer diagnoses or treatments to interfere with their vacation plans. In fact, they seem to use their vacations to get some distance between themselves and their situations.

Other times, members discussed the instrumental aid they received from others – health care professionals, friends and family – that helped them deal with difficult circumstances. In the following example, Melanie discusses the relief she feels to have the help of her Hospice nurse:

> "I have a home health nurse from Hospice who comes and helps me twice a week, which I am so grateful for," says Melanie. "You have a hospice nurse, Melanie?" asks Jeanne cautiously. "I do. He's great. He came in and got all my medicine organized for me. I don't know what I’d do without him," says Melanie. "Your insurance will pay for nursing care during chemo, but not after," says Patsy for clarification. "With Hospice everything is free and I don't have to pay a dime," offers Melanie.
>
> – socio-emotional group, TN

Ann Marie has just been diagnosed with a metastasis from her breast to her spine. Her co-workers rallied to her side, taking up a collection to buy her a comfortable chair for her ailing back:

> "Tell them about the people at work," says Keith. "The people at work have been amazing. They're like my second family; they have been so good to me. They wanted to buy me a chair for my back. I went to the store and the one that really felt the best was this incredibly expensive leather chair. I told the salesperson that cost was too much and he gave me a whole stack of [less expensive] fabrics to look through. At that point I felt completely overwhelmed and went home," says Ann Marie. "And they bought you the leather chair anyway," says Felice. "They did or least one person did and the department will pay her back, but that's not all. One woman at work opened a checking account in my name and they've put $2,000 in it already..."
>
> - socio-emotional group, TN

Ann Marie continues to describe the great difficulty she has with sitting comfortably anywhere, including the toilet:

> "The toilet is really difficult for me to get on and off. My dad is so sweet. He built me a little stool for my feet for when I sit at my computer. I had to get Keith [fellow group member and boyfriend] to bring it to me while I was on the toilet so I could get back up. I have a roommate who lives with me three days a week and the stool is still in her bathroom. Oh well. Fred also told me about the special toilet seat you can buy," says Ann Marie. "You need the cushioned kind," says Patsy. "You can get those at a medical supply store," says Fern. "Fred says they are cheaper at Walgreen's so that's where I'm going to go," says Ann Marie.
>
> – socio-emotional group, TN

Ann Marie receives tangible aid from both her father and fellow member turned boyfriend. Other group members offer advice as to where she might find an elevated toilet seat to help her out further, another form of informational problem-focused support.

The following week, before Dale has a chance to speak in this week's session, Agnes freely offers her assistance interpreting Dale's words:

> "Last week.....I kept finishing Dale's sentences for him. I told him that the next week I'd sit right next to him. That way between the two of us we can have one continuous sentence. Right, Dale-ster?" says Agnes smiling at Dale. "That's right," says Dale smiling back. "You'll just be one continuous loop of conversation," adds Diane. "He could think of the word before I could," says Dale in his slow, garbled speech. "She! She! I'm not a

> he," says Agnes patting him on the arm. "Huh, what?" says Dale clearly confused. "I'm not a he, I'm a she even though I sound like a he with my deep voice," says Agnes. Dale pauses a few moments just staring at her, "Oh I apologize! I'm just stupid," he says. "That's okay. It happens all the time," she replies good-naturedly.
>
> – socio-emotional group, TN

Dale appears to appreciate the help Agnes offers him. Even when Dale mistakenly refers to Agnes as a he, she assists him by relabeling his own feelings ("stupid") in terms of her own shortcomings (sounding and appearing more masculine). In this way, she has also provided cognitive emotion focused support in conjunction with behavioral problem-focused support.

Within the group, individuals offered their own advice about a particular problem or situation to fellow members. At times, members sought out specific others to help them deal with a problem. For example, Ann Marie recounts for the group why she had to enlist Jeff's help the previous weekend:

> "And while we're on the subject of bowels, I had to call Jeff this weekend because I couldn't poop and I knew he would know what to do. I'd feel like I had to go, but I'd get on the toilet and bearing down was just too painful. I was in so much pain because I couldn't poop and it kept getting worse! Poor Keith, I sent him out late at night to get me everything he could find, including those glycerin suppositories Jeff told me about. I didn't need a hundred just a couple. I almost called you back at 2:00am to tell you I had been successful," says Ann Marie to Jeff. "Oh god," says Jeff placing his hand on his forehead.
>
> – socio-emotional group, TN

Although Jeff has a different kind of cancer than Ann Marie, he had dealt with the same problem himself and could advise her appropriately. Sharon, tonight's leader for the lymphedema information group, passes along the following advice:

> "Use your common sense here. If you decide one day that you are going to spend hours raking your backyard and you experience serious pain, then you know not to continue. Some people think their house needs spring cleaning and spend hours scrubbing or

> mopping. These may be things that you used to have endurance for, I know. Just take it easy. Do things in short spurts or come back to it," says Sharon.
>
> – informational group, TN

Patsy solicits advice from the group on behalf of a friend with cancer:

> "I have a question to ask the group. I wanted to be sure to remember it," says Patsy immediately after Fern leaves....A friend of mine from Sunday school has melanoma. She's been receiving treatment for the past five months and lately these horrible blisters have appeared inside her mouth. Have any of you had a similar experience or know anything about mouth blisters?" asks Patsy. "There is a mouthwash called Magic Mouth that's supposed to work real well, " says Mary Pat. "Can you get that over the counter?" asks Patsy. "No, you have to have a prescription. She can also use yogurt which works well also. You can't use the kind with the fruit in it because sugar will just fuel the blisters," says Ann Marie, a nurse.
>
> – socio-emotional group, Nashville

Patsy seems to know that the experiential expertise of the group can provide an accurate answer to a fellow cancer patient's question. As all of the coping assistance sought by group members suggests, similarly situated individuals may be in the best position to offer effective coping assistance (Thoits, 1986).

But significant others can and do step in, too.  The assistance provided by Paulette's children relieved her of her husband's care so that she could get the medical help she needed to take care of herself:

> Becky, the facilitator, says, "Paulette, you never finished telling us about yourself. What about your cancer? You don't have to go back for anything?" "No, it's fine. I'm just so very fortunate, so fortunate because at the time [I was diagnosed], Will [her husband] was very, very sick as everybody knows. He was on chemo and everything and he was so weak. If I hadn't had Sadie, James and Terry [her children], I don't know what I would have done for help....so everything is just fine – I just can't believe it. So far, so good. It was just so quick. I went to that first support group meeting..." Her daughter Terry interrupts, "She already had the surgery done!" "And before the next meeting," adds Paulette. "Like nothing had happened," says Terry.

> – socio-emotional group, FL

Hearing about another patient with bone cancer who had a serious bone break causes Jeff to be more cautious:

> Sarah inquires about Jeff's progression. "I have to go in for a complete bone scan in the next couple of weeks," says Jeff in a positive tone. "How do they do the scan?" inquires Sam. "Well, it's actually a series of x-rays from top to bottom to check for any breaks. I've got a rare kind of bone cancer where your bones can break really easily. I heard of a guy with my cancer who rolled over in bed and broke his back. I actually broke a rib in bed, so I have to be really careful." I hear other people talk among each other as Jeff's explains the procedure to Sam...
>
> – socio-emotional group, TN

Although judging by his partner’s reaction, the nurse’s advice seems completely wacky, Paul still wants to give it a try to see for himself if it works:

> "The nurse told me to jump up and down on a trampoline to drain my lymph system. So I really thought about going and getting a trampoline," says Paul. "And wave a chicken wing around your head three times!" adds Betsy swinging her arm around her head. "I can't believe some of the things they tell you to do," she says aghast. "Wave a chicken wing in the air at midnight in front a full moon to the sound of drums and then drink a concoction made of bats and two teaspoons of period blood." Betsy throws her hands up in the air in exasperation. "I've tried the tapes, meditation and now I am doing yoga," Paul continues to the rest of the group.
>
> – socio-emotional group, FL

Although Paul seems to be willing to take the nurse’s advice, his partner Betsy does not support him.

Fellow members could assist with others’ problems by helping them think about them differently when the situation could not be changed.  For example, Nanette worries that the demands of her chemotherapy many be overwhelming her husband.  Group participants try to ameliorate her stress through reinterpreting her problem, bringing her thinking back in line with putting herself first:

> “I worry about my husband working so hard to take care of me. I mean what if he dies of a heart attack taking care of me?" says Nanette...."Let your husband and your family take care of you right now. Don't feel guilty about it," offers Patsy. "And you were the one, Patsy, Ann Marie kept having to tell not to feel guilty about her family taking care of her!" "I mean I can't imagine what you're going through right now and I know what I went through doesn't compare to your experience," says Bob. “I think getting an extra three months with your grandkids is worth the month of chemo. I mean that's what I would do."
>
> – socio-emotional group, TN

Rather than worry about her husband’s well-being, fellow members urge Nanette to focus on getting the care she needs to live longer.

Jeanne’s co-worker suggests that through her own doing she brought cancer upon herself. Fern swiftly responds to his threatening allegation that Jeanne may have brought cancer on herself:

> "My boss told me that I was to blame for getting cancer. He said, my wife's never going to get cancer. She eats everything she's supposed to. I told Earl, that's nice but you don't get to control cancer, cancer controls you," says Jeanne. "Good for you," says Fern, "Next time he says anything like that, tell him to come here first.”
>
> – socio-emotional group, TN

On occasion, group members would look back to the time before they were diagnosed to determine if there were warning signs they should have heeded. In this rather lengthy exchange, Bob questions aloud had he taken better care of himself earlier would cancer have never developed:

> Bob wonders aloud if anyone thinks a stressful experience may have precipitated their cancer. Caroline exclaims, “Absolutely!” “Caroline, right before your recurrence, you had that stress you were talking about [her sister died]. “We knew she was going to die and then she did. A month later I had another surgery.” “You hear a lot of them where a woman has leukemia and her son comes home from college and she goes into remission. He leaves for college and the cancer comes back.....I was just curious about how everybody relates stress to their own lives. You hear it so often. People retire or they give up a certain lifestyle and all of the sudden, the cancer starts to bloom,” says Bob. “A lot of people say cancer is a long term thing. You don’t just get it one day. You’ve probably been living with it for a long time before it develops, so what period [of stress] are you looking at? I was thinking about the same thing, reading books about stress and wondered how long have I had this?” says Gayle. Becky, the facilitator, responds, “There may be [a relationship between cancer and stress]....It’s very difficult to draw cause and effect in something like that for one of the reasons that Gayle just said. We don’t know how long cancer germinates in the body before it is detected. And the reason I really like to emphasize that is because I see that people begin to focus on the idea that, ‘oh my god, I got cancer because I didn’t handle stress well enough. It’s my fault.”
>
> – socio-emotional group, FL

Although Caroline agrees with Bob’s thoughts on stress and cancer, Becky the facilitator disagrees with their assumption that invariably leads them to self-blame for a condition they cannot control, creating further stress. Bob and Caroline believe they failed to listen to their bodies and Gayle and Becky correct their deviant thinking. The notion of listening to one’s body appears to have its limits and, in this case, cannot be appropriately or usefully applied retrospectively to the cause of cancer.

Patsy talks about her confusion over the research regarding vitamin supplementation and cancer:

> "While we're on the subject [of homeopathic remedies] and I hate to even bring this up, but I brought an article on antioxidants. They think now that vitamin C may actually contribute to cancer growth and I think maybe a couple of other vitamins, too. It's so defeating. Here I've been taking tons of all these vitamins and something like this comes out," continues Patsy. "But then you have to weigh how the study was designed, did they use an adequate methodology "says Ann Marie. "Oh yeah, I know all that, but it's hard to know what to do."
>
> – socio-emotional group, FL

Patsy believed she was helping her body fight her cancer through the use of much touted antioxidants. The revelation of research that contradicts her thinking proves threatening. Even Ann Marie’s attempt at cognitively reframing the information to be less credible does not reduce the confusion for Patsy.

Others can assist members to change the meaning of a situation through cognitive reframing or members can compare themselves against others who are better or worse off as a means of self-evaluation or self-enhancement. Upward social comparisons can demonstrate to an individual how she can improve from taking good care of herself, or, as seen below, that she should have been able to manage more than just her illness. Sam realizes that she did not function as well during chemotherapy as others did:

> Bob says, "I worked the whole time. I worked through chemo and radiation, but you forget that I was in the hospital for six months." "Yeah, as I said I only took two months off for my chemo, but they were pretty understanding," says Ann Marie. "I feel like I wimp compared to everyone else. I didn't work at all," says Sam privately to me.
>
> – socio-emotional group, TN

Although Sam behaved appropriately given the norm to re-prioritize, she still feels like “wimp” compared to others.

In general, with respect to the principle of listening to one’s body, members appeared to offer coping assistance in the form of information and advice foremost, followed by instrumental assistance, and, on occasion, cognitive reframing.

### It Is Important to Maintain a Positive Outlook

Maintaining an optimistic outlook on one’s future inspires and encourages persons with cancer who come to the groups looking for hope despite whatever odds of survival they may be facing. Although this principle and its attendant norms did not appear to be supported by direct behavioral intervention, the circumstances could at least be cognitively reappraised as less threatening. For example, even when the odds are against her, Ann Marie tries to put a positive spin on things:

> "We were reading about Ann Marie's back surgery, but unfortunately, the studies only follow people six months out of surgery at which point everyone dies. And this is a recent study -- March, 2000," says Keith. "Yeah, so that's not all that hopeful. Let's hope I live a little longer than that," adds Ann Marie.
>
> – socio-emotional group, TN

Martin considers his cancer a more favorable situation when compared to more threatening situations in which he has found himself:

> "Believe me, I've had LOTS of near disasters [his emphasis]. First I fell seventy feet off the back of an aircraft carrier, then a 500 bomb landed on the wing of my plane, and then I got sucked into the intake shaft [or engine, I'm not sure which] of an airplane. If you don't call those close calls then I don't know what is. I'm not about to let this little bug do me in," says Martin.
>
> – socio-emotional group, TN

Martin’s comment upholds one aspect of thinking optimistically -- maintaining a fighting spirit. Becky, the facilitator, explains the importance of a fighting spirit further:

> “I would [say] that certain people have a certain drive to survive. Well, we all have a drive to survive, but it’s on a continuum.” “From low to high,” says Bob. “Yeah, I think from low to high and I think some people have a much higher drive to survive on this planet and I think that varies with life circumstances too. But it’s this drive – it’s kind of an intangible thing. I mean Caroline is a great example.” “Some people, if they take one doctor’s word [unquestioningly] and they don’t get a second opinion, that’s a big difference,” says James. “They might have the drive, but they accept this doctor...” he adds. “It’s about searching for what [will give you the best outcome]. I agree with what James is saying, particularly when you have two doctors who don’t agree,” says Becky. “Remember the girl in the coping class that had melanoma? She had that one doctor and [the class] emphasized how important it was for her to get another opinion. I guess she did,” says James. “I mean [doctors] are not gods. They can’t tell you when you’re going

> to die or what's going to happen down the road," says Bob. "Well, one of my favorite sayings about doctors is that doctors are experts, but they are not clairvoyant. When someone says, well, that's irrelevant, I want to question where that statement comes from knowledge -- or lack of knowledge," adds Becky.
>
> – socio-emotional group, FL

As Becky indicates, those with a strong will to survive will not settle for one doctor's pessimistic outlook, but will search for the doctor who gives them the best prognosis. In other words, members should find a doctor who can re-evaluate their situation so that it appears to be less threatening. This tactic also supports the ideological principle of taking charge of one's treatment.

When reinterpreting the situation will not work, group members try distraction. Using humor, Bob, Keith, and Sam try to divert Jeff's attention from the real reason he qualified for disability:

> "I got full disability after all. Do y'all remember me talking about that? Even the lawyer told me that I wouldn't get it. Actually, it scared me a little bit," says Jeff. Bob makes some wisecrack and adds, "At least it means you won't ever work again." "You can't," says Keith. "I guess they don't expect me to live for very long if they gave it to me," replies Jeff. "And the sooner, the better," adds Sam joking. "Yeah right, I guess the sooner the better," he says laughing.
>
> – socio-emotional group, TN

Focusing on the positive requires reinterpreting one's emotional reactions to cancer, too.

Caroline appears defeated by the lack of energy and memory loss she has experienced lately. Paulette offers another (non-cancer) attribution for her physical state:

> "I am so used to having endless energy. I've never run out of energy before," says Caroline slumping down in her seat. "You're getting older, Caroline. Age will slow you down. Nobody's as active as they used to be," says Paulette. "Older?!" says Caroline seeming genuinely shocked by Pauline's suggestion. "Aha! I remember now! The

> address is honorroll@march.org. I'm not losing my mind entirely after all." So for now, Caroline seems reassured about her mental well-being....
>
> – socio-emotional group, FL

Members engaged in their own comparisons with situationally and/or experientially similar others to assess their relative well-being. Group members appeared to select their own targets for comparison or others offered comparison targets with whom they thought the distressed would find useful. Bill gives thanks for the relative lack of side effects he experienced compared to other group members:

> "Stress is very important and I think you do that to yourself. I just had the blood test [for prostate cancer] and I go Tuesday and I would be disappointed if it wasn't way down. It went down 90% just with the two months of the hormones. When I'm in here I find myself out here with the other people [not sure what he means exactly] Caroline who's not here it's been seven years on chemo and the other gal who was radiated on the throat, couldn't eat, couldn't taste. I sit here and think I have nothing to complain about relative to other people," says Bill.
>
> – socio-emotional group, FL

Similarly, Helen gains inspiration and motivation from a friend she considers to be in worse physical shape:

> Helen again abruptly shifts the subject to a friend of her cousin's who has serious rheumatoid arthritis and cannot not bend her knees or her wrists. As a result, she has to sleep upright and use an instrument that looks like an elongated spoon to feed herself. "She's into crafts, well I just got into crafts about three months ago, and I found that I couldn't do something. She said to me, 'If I can do it, you can do anything.' And she was right. I mean how could I complain after that?" She laughs at herself again. "She [the rheumatoid arthritis woman] does all kinds of stuff and her doctor tells her to go do it. I asked my doctor if I could take a trip and he said to me, 'Go, go' (She makes a broad sweeping gesture with her arm.) So my husband and I took a big road trip to Denver, Colorado."
>
> – informational group, FL

Fellow members can offer comparison targets for those whom they perceive needing assistance. Sam and Sharon reassure fellow member Susan about her symptoms, comparing her to a friend with the same condition:

> “Once you have lymphedema, it's upsetting because there is no known cure and it's harder to manage," says Sharon, the facilitator. Susan expresses concern about feeling like her right arm has grown large, even though she knows she's big already. "Oh no, I have a friend at work whose arm is twice the size of yours," says Sam reassuringly. "Sounds like your friend might be into elephantiasis," adds Sharon, the facilitator.
>
> – informational group, TN

Dorothy brings up a scary subject, namely the lack of a “cure” for cancer, but Babe tries to soothe her distress:

> "My doctor told me that once you have breast cancer that you are never cured the rest of your life. You just never know if it's going to come back or not," says Dorothy. "Some people are lucky and it never comes back. I knew this woman who had a brain tumor about twenty years ago, had surgery, and hasn't been to see the doctor in twenty years. She's cancer free," says Babe.
>
> – informational group, FL

Nanette, a support group participant, is absent this evening due to the death of a close friend’s husband. The death hits close to home for Bob:

> “It's a horrible story. Did you all hear about this?" asks Sarah. "No, what?" says Bob. "It was one of the two friends who comes with her to group on Monday nights and attends the [friends and family] group upstairs. He was riding his motorcycle and fell off a cliff over the weekend," says Sarah. "Oh I did hear about that!" exclaims Bob. "I went to school with that guy. He didn't actually go over the cliff on his bike. He was with his brother and his son, I believe, and they had gotten off their bikes to hike around. He and his brother had separated and when his brother called his name, he got no response. I think they found his wallet or something so they knew he had gone over the cliff," says Bob. "You knew him?" asks Sarah incredulously. "Yeah. He was in the construction business a while back, plus I gone to school with him as I said. Plus [he says with great

> emphasis], anytime a 52 year old guy dies, you bet that's the first thing that catches my eye because that's my same age!" says Bob.
>
> –socio-emotional group, TN

Rob felt threatened not by how the friend died, but the age at which he died.

Appropriate comparison targets were not always available for those searching for them, creating uncertainty and fear. Peter describes his attempts at finding a similar other with whom he could compare himself:

> "I called the hotline established by Richard Block [of HR Block, a two time cancer survivor who wrote a book on beating cancer] and asked to speak to melanoma survivor. The woman put me on hold for ten minutes, came back and said that she couldn't find anyone," says Peter with his eyes wide. "She said that they just didn't happen have someone on hand and gave me the number of MD Anderson in Houston. A guy called me back that same afternoon. He had been one of the youngest melanoma patients on record who stayed cancer free until he was 44." Peter seemed buoyed by the conversation at least temporarily. "When we were researching cancer centers we talked to a lot of patients about their experiences," says Katie...
>
> – socio-emotional group, FL

The perception of situational similarity prompts Sam to seek out a specific member in order to enlist her help in understanding new or strange symptoms:

> "Nurse Ann Marie, I have a question for you. I have started having these shooting pains in my arm [side of her body where she had the mastectomy]. It doesn't hurt all the time, but I'm not sure why I'm having them," says Sam. Ann Marie runs her hand through her hair, "It's funny you say that because I have been having the same thing. It hurts to press there, but doesn't ache all the time. I think those are spots of fibromyalgia. I realize that I need to be exercising my arm more because I stretched it the other day and my whole side cracked. I thought, 'Uh oh.' You're supposed to exercise so you don't favor one arm over the other." Ann Marie explains about the excessive buildup of scar tissue...
>
> – socio-emotional group, TN

Sam turns to Ann Marie, a fellow breast cancer patient and nurse, who offers advice based on her own experience and nursing training.

The coping assistance efforts shaped by this ideological belief consist of cognitive efforts to manage both an individual's situation and the emotions stemming from the situation. In an effort to focus on the positive, members put a favorable spin on unfavorable circumstances or urge keeping up a fighting spirit in order to contend with an unfortunate situation. They also engage in social comparison for guidance and for self-evaluation, both of which potentially contribute to maintaining a positive outlook.

### Support Groups Offer Safe Haven

The norms of making others feel good, receiving sympathy and concern from other group members, venting frustration and complaining, and being able to appear deviant in physical appearance deviance all support the ideological belief that support groups function as a safe haven for cancer patients. Believing in this ideological principle allows cancer patients to be – and to come – as they are to receive positive emotional support without fear of rejection.

As seen in the previous chapter, many of the norms examples also contained examples of coping assistance as well. The types of coping assistance that predominated with respect to the norms of safe haven appeared to modify a person's emotional responses such as the provision of positive feeling through sympathy, concern, listening, acceptance of a deviant appearance, and just being there. In this section, I will discuss additional aspects of coping assistance not mentioned earlier that enforce the belief that support groups are a safe haven.

On a single occasion, an instance did occur where a member permanently left the group on her own accord because the group discussion had become too threatening as she underwent her treatment for breast cancer. The group discusses Dori's recent departure:

> "As I recall, one of the reasons Dori gave for leaving this group was that she felt overwhelmed by some of the things we talked about," says Martin. I add that perhaps Dori felt as though she was hearing too much information about cancer, making her feel fearful. [Diane, the facilitator, earlier relayed that Doris would rather not get any more

> information than she absolutely needed to get through her chemo. Dori explained that once the ordeal was over, she could then go back and reexamine what she had undergone. The group seems quite defensive about her departure, taking her remarks as a personal affront.]
>
> - socio-emotional group, TN

Dori apparently wanted to control the kind and amount of information she acquired about her circumstances as a means of managing her own stress level about her cancer. When she could not think differently about the information she heard, she avoided the situation altogether by leaving the group. In this instance, the group was not a safe haven.

In order to prevent the further exacerbation of her anxiety, Mary Pat tries to curtail the discussion related to a surgery she must have on a wound that will not heal:

> "I was supposed to have the surgery to sew up my wound [from her mastectomy] on Feb. 26th. I went to see another doctor [for a second opinion] who told me that I'll need *two* surgeries," says Mary Pat. "What?" exclaims Bob. "I felt so devastated to hear that. This doctor tried to tell me that he had the utmost respect for my first doctor," she replies "You know the other Patsy had to have four," says Jeanne knowingly....May Pat moans and holds her head in her hands. "I am not in a place psychologically to accept that I need two more surgeries. There are all sort of little details related to the surgery that I don't feel like talking about right now, so I'll leave it at that." Mary Pat clearly seems to be signaling to the rest of us that she does not want to discuss her wound further...
>
> – socio-emotional group, TN

Although Mary Pat shares with the group that she needs additional surgery, she also signals to the group that she does not want to think about her situation any further**.** She has manipulated the situation at least temporarily to reduce threat and to control her distress. The group appears to respect her wish to change the subject of conversation.

On occasion humor works to change a stressful situation by distracting individuals from the more threatening aspects of their cancer, thus serving as an example of cognitive problem-focused coping. Jeff offers a more playful and thus distracting answer to Sam's serious question:

> "I have a strange question for you, Anne, but what does it mean to be six months out?" asks Sam earnestly. "You mean six months out of the closet?" says Jeff. Everyone roars with laughter, especially Jeff and Ann Marie. "You know I do have this new short haircut," says Ann Marie. "And you are wearing practical shoes!" adds Jeff. More laughter ensues...
>
> – socio-emotional group, TN

Implicit in seeing the humor in a situation is changing one's thinking and improving how one feels about a situation.

Fellow members could also assist one's coping efforts by being a comforting presence. Members describe how the presence of children and partners in their lives provide a reason for living:

> "These children are our lifelines," says Martha clutching her fists together. "You've got Jim, Gerald has Gianni, and you've got Jacob," says Bianca to Martha. "James Delmar Jones," says Dale looking off into space. "And of course you've got your little grandchildren, too," says Diane to Bianca. "Oh sure, we get them every other Friday night and Sundays, too. There father works a night job and so we take them in order to let him sleep." Bianca talks about what she and her husband do when their grandchildren come over and how the kids are saving change for a trip to Disney.
>
> –socio-emotional group, TN

> "Now that Kara works, I'm the one home with Gianni all day. He follows me around wherever I go and now he's closer to me. We sit together on the couch and watch television. He's my biggest source of support without a doubt," says Gerald about his son.
>
> – socio-emotional group, TN

Members themselves could be a comforting presence, too. Mary Pat seems particularly touched by the two male group members present this evening:

> "You two are just amazing," Mary Pat says turning towards Kevin and Bob, who happen to be sitting side by side. They look at each other with bemused, but somewhat bewildered expressions on their faces. They seem to realize she is paying them a huge

> compliment. "I can't believe how supportive you are! I know this sounds terrible, but you're men!" says Mary Pat, sounding surprised and looking around to the rest of the group (all female tonight). "How often does that happen?” she says...
>
> – socio-emotional group, TN

The mere presence of a person boosts members’ sense of being loved and needed. The supportive presence of Kevin and Bob also underscore the perceived availability of appropriate support from the group when needed, which contributes to the perception of groups as safe haven.

Although members may reach out to others to supply positive feeling by throwing a birthday party, for example, not everyone agrees with their intentions. Kevin may have been allowed to visit, but he suspects that the highly protective mother would block further supportive attempts:

> “There's another little girl down the hall from her that's not doing as well who said she wanted to have a birthday party just like Michelle's." "I'd love to come visit her and bring my [Bopper] game. I just love that game. You twist it and pull it and it makes noises. I can't put it down and it drives my daughter crazy," says Mary Pat. Did you say, Bobbitt?" says Bob pretending to be incredulous. I correct him and everyone laughs. "Since I work on campus, I can get away virtually anytime," says Mary Pat to Keith. "I just don't know if the mother will let anyone else into the room," replies Keith. "Wow, that's really too bad," muses Patsy.
>
> – socio-emotional group, TN

Although Keith may have been a positive, supportive presence for the child, he was not able to do the same for the mother.

One of the advantages to attending a cancer support group is the readily available pool of persons with situational and experiential similarity along a number of dimensions. Members empathized among themselves about the side effects that they experienced from their cancers:

> "Plus, what is up with this fatigue? I am tired all the damn time. I had to go back to bed this morning at 10:00am after getting up earlier," Patsy adds with a sigh of exasperation. "I know. It's a kind of fatigue that's hard to explain to other people. It's just feeling of bone weariness that can't compare to anything else," Ann Marie empathizes. "I mean when you say you're tired, you have to go bed right then and there," Ann Marie adds. "I feel like I have chronic fatigue syndrome," replies Patsy. "I know what you mean. I do have chronic fatigue AND fibromyalgia on top of having cancer!" exclaims Julie.
>
> – socio-emotional group, TN

> "With this type of cancer having diarrhea twenty times a day is completely common and there were days that I couldn't leave the house. With [medication name] I only had diarrhea six times a day which for most people sounds horrible, but hey, that was a major improvement for me!" exclaims Jack. "I'm with you, buddy. I don't have what you have, but come tomorrow [after chemo] I won't be able to leave the house all day long," says Martin extending his hand to Jack. Jack and Martin have a good laugh together as they shake hands.
>
> – socio-emotional group, TN

> "Morphine," says Jeff wistfully. "Jeff just rolled it up and smoked it," jokes Bob. "I took it every day for a year. I went into the hospital and every time I said 'ow' they gave me one shot [of morphine] after another. I was so high I had to stay in the hospital for a week!" "I even pooped on myself in the hospital!" says Nanette exasperated. "I did that, too" says Jeff. "They had to put me in a great big diaper," says Nanette. "Yeah, I didn't even have a diaper. I did it in my bed," he says laughing. I told my husband that I feel like a big ol' Jackson - that's the name of my little grandson," she adds. "A big ol' Jackson! That's cute!" exclaims Bob. "Yeah, having cancer is absolutely so shitty," says Jeff. "I had to stay in the hospital for my chemo just like you."
>
> – socio-emotional group, TN

Members could also empathize about the unusual circumstances surrounding their diagnoses like Martha and Bianca:

> "If you take your hand a make a fist, your spleen is basically about that size without your thumb. It weighs about three ounces. My spleen was ten inches long, four inches across and four inches deep. That's how big it got. The doctor says that having an enlarged spleen feels a lot like being pregnant. I noticed that my waistbands were not fitting and were riding high on my stomach. When they finally removed my spleen it weighed

> something like three and a half pounds. I thought my spleen weighs more than some premature babies!" says Bianca. "I know how you feel. My tumor weighed four pounds when I finally had it removed," says Martha who has ovarian cancer. "Then again, who ever thought I'd get pregnant with Jacob at 42?" she adds throwing her hands in the air.
>
> – socio-emotional group, TN

> "My cancer didn't even appear on my mammogram," says Patricia. "Mine didn't either," says Margaret. "I had this friend of mine call me up the other day and say, 'Margaret, you, Louisa and I need to start our own support group. I thought, what in the world? I knew my friend had breast cancer, but not Louisa. Turns out she just got diagnosed. She had a history of those breast lumps, you know? When she was about thirty they [lumps] showed up and the doctor always told her they were benign and not to worry. Well, they never went away and she started to worry when one of them started to harden. It still never showed up on the mammogram as cancerous. They had to do a biopsy before they knew she had cancer."
>
> – socio-emotional group, TN

Depending on the dimension under threat, Margaret demonstrates how members could get highly specific with regard to perceiving situational or experiential similarity.

Nanette complains about the unusually complicated port implanted in her chest. [Ports work like a direct intravenous line to deliver chemotherapy into the heart and then pumped into the rest of the body.] Bob, who happens to have the same complicated port, offers himself as a target for comparison:

> Somehow Bob and Nanette manage to discover that they both had the same doctor for their port installations and that's why they have the same, unusual port. "Sure you don't want to let me see so we can compare handiwork?" "All right, you really want to see my port? I'll show it to you!" says Nanette. She quickly removes her jacket revealing a tank top turtleneck underneath. She pulls her top over to one side to expose her scar. "See?" she says. Her port resembles a pacemaker. I can see something round just below the skin and then two incision scars on the top and the bottom of the round bulge in her skin. "That's looks just like mine," says Bob. “Mine's bifurcated and I've got two nasty scars. I mean what a horrible thing to do to a woman's chest," says Nanette. "Mine's just like yours," says Bob. "You've got two incisions, too?" replies Nanette. "Yes, and I've got the tube going this way up into my neck. I'll show you mine if you show me yours," Bob says suggestively. "Don't worry my wife's upstairs," he adds. "No, I not going to show

> you it! I'd have to take my top off for that," says Nanette. "We can go into the bathroom. That's no problem," replies Bob with a big grin.
>
> – socio-emotional group, TN

Misery does love company; however situational similarity can have its limits. For example, Keith presumes that everyone has a scar to show off from some sort of cancer-related surgery:

> "I'm telling you we need to have scar night where we all sit around and compare scars," says Keith. "Of course, everyone can see mine since it's on my head," he says pointing to his forehead. I cannot see anything from where I am sitting. "We could give prizes for the biggest scar," says Mary Pat. Patsy gives out a big groan. "Hey, that's not fair, not all of us have scars," laughs Jeff.
>
> – socio-emotional group, TN

In the exchange below, empathetic understanding again has its boundaries and Bob’s apparent insensitivity underscores that having a cancer diagnosis in common is not enough. Karrie talks about how her plastic surgeon went a little too far in reconstructing her breasts, making her nipples too prominent:

> "But you don't want them that way all the time," retorts Karrie good-naturedly. "You could never work around middle-school aged kids and have that," says Patsy shaking her head, "That would be a complete disaster." [Patsy is a retired middle school principal] "You can imagine what it's like to walk around in a bathing suit like that. It's so embarrassing!" exclaims Karrie. "Are there any female plastic surgeons around?" asks Patsy eagerly. "A few, but only a few," replies Jeanne. "I've seen so many pictures, too," says Patsy. "Ooh, can you bring them in with you?" says Bob suggestively. "They're not like Playboy pictures, Bob. You probably don't want to see them. They've got scars all over them," says Karrie laughing. "That's true. My stomach is the same way. Damn!" he says. "You see breasts every which way," says Patsy looking a little squeamish. "You can just have them shape the breasts. You don't have to have a nipple put on," offers Jeanne. "You mean they can't just put your nipples right back on?" asks Bob. "No, they have to tattoo them on," corrects Jeanne. "So you don't have any feeling in them?" asks Bob. Jeanne and Karrie both say no. "Well at least you could get them tattooed cool colors like

> one red and one blue," he offers playfully. "Just tell him you want little ones. Plastic surgeons know how to make an A cup," says Jeanne knowingly. "That's all I need..."
>
> – socio-emotional group, TN

This particular group, like all the socio-emotional support groups, consists of patients with different kinds of cancer at different points in their treatment. Bob's gender and cancer (pancreatic) impede his ability to validate his fellow female group member's feelings about breasts. The women seem to overlook Bob's lurid comments and jokes because they have each other to offer appropriate advice.

The groups also could assist members who expressed worry or concern by allaying their fears through using their own experiences as examples. During one group meeting, members discuss their post-treatment fears. Both Eddie and Bob worry about what to anticipate once their regularly scheduled treatments end:

> Eddie asks, "Do you ever get scared when they tell you do don't have to come back [to see the doctor] anymore? Do they feel like they can do nothing more for you?" "No, no, no, I mean when you go everyday [his emphasis] in this routine with the three gals [nurses] and the doctor, there's just a kind of momentum in that. You're such that you don't think about it at all....You wake up and you don't think about cancer. I'm just wondering if that will change [when I don't have to go to the doctor so often]. Maybe knowing that might happen, maybe I'll be able to watch for that [sic]," says Bob. "What did other people experience?" asks Becky, the facilitator. "Yeah, yeah, I was just going to say that I had fallopian tube cancer. I had chemotherapy for six months, second look surgery, more chemotherapy and then I didn't have anything [after that]. I made out just wonderful [sic] and I don't have anything now and I'm, like, on three month visits.... so it's kind of nice," says Gayle.
>
> – socio-emotional group, FL

Gayle's post-treatment experience has been a positive one, which hopefully bodes well for Bob and Eddie. Becky urges the rest of the group to share their experiences as well:

> Becky, the facilitator, asks the rest of the group, "So when you look back at when you finished your treatment, what was that like for you?" Fred, the husband of May who has

> breast cancer, says "I'm surprised. I don't think it changed her. The day after she got out and when she had her [mastectomy], I came up [to the hospital] figuring I'd see her suffering in bed. Instead, she was sitting up, you know? I was the one who was stressed!" The rest of the group laughs. Bob says, "Sounds to me like you're being too successful with this group, Becky. Everybody's healthy or getting well! You might make yourself unnecessary if you are too good at this, you know."
>
> – socio-emotional group, FL

Fred surprisingly found himself more worried than his wife who underwent a mastectomy. Bob interprets May's and Gayle's relative lack of distress as a positive sign that the group (namely the facilitator) works well to dispel uncomfortable feelings.

In sum, the techniques of coping assistance that uphold the ideological principle of safe haven are composed of a variety of strategies. The situation could be altered either behaviorally or cognitively in order to reduce threat. Members empathized with each other about their situations or side effects, but appeared to empathize with those whom they felt situationally similar (beyond just having a cancer diagnosis). Another coping assistance strategy that reduced anxiety and promoted the maintenance of positive feelings was learning from each other, particularly about what to expect in the post-treatment period. However, the coping assistance technique that predominated with respect to the ideological principle of safe haven was emotional support based upon empathetic understanding and situational similarity.

### Stigma

Certainly not all events discussed by the support groups can be encompassed by ideology or by norms. As mentioned in chapter one, I suggested that through their interactions with others, persons dealing with stigma may come to see themselves, their feelings and reactions as deviating from the norm. Cancer as a stigmatizing condition has been well documented in the research literature as contributing to the avoidance, dismissal, and mistreatment of cancer patients by healthy others. Significant others may feel too threatened themselves to render appropriate coping assistance at a time when cancer patients require it most.

To my surprise, problems in coping with the stigma of cancer were rarely mentioned by the group members, even by those who were newcomers. I expected to find more evidence supporting my supposition that cancer patients would feel motivated to seek coping assistance from support groups to deal with their feelings of being stigmatized. Only Eddie and Gayle discuss how feeling different prompted them to come to a support group:

> It's good joining the group because you think you are different from other people, huh?" says Eddie. "Well, I didn't know. I thought I was just like everybody else. Am I denying this, you know, or I am I going to wake up one week and go, ahhhh!" replies Gayle.
>
> – socio-emotional group, FL

Eddie states one aspect of the stigma of cancer – that one thinks one is different from other people. By coming to the group, he realizes that he is not alone in experiencing the ups and downs that characterize a cancer diagnosis. Support groups can aid in managing the tension between members and the outside world by cognitively reframing one's feelings so they seem normal and reasonable.

As noted in chapter one, one of the most unhelpful behaviors reported by cancer patients is the withdrawal of loved ones. Mary Pat tries to prevent this from happening to her by pretending to be in better health than she is:

> "My brother only wants to hear that I am improving and that's what I tell him. I don't bother to tell him otherwise because I know that he can't deal with the truth,"she says. "You've never told him your status?" asks Sarah, the facilitator. "No, I haven't," she replies. "What's the point really? He doesn't want to hear the truth. I can't really depend on him [to help with child care]. I have someone else who looks after my daughter."
>
> – socio-emotional group, TN

Mary Pat alters the information she gives her brother as not to upset him and thus create more stress for herself. By protecting him in this manner, she shields her brother from the threat her cancer poses and she also protects herself from feeling rejected.

Unlike Mary Pat, Katie discloses her true condition (being bald), causing her nieces to recoil physically from her:

> “My little nieces are so funny about my hair. When I told the younger one I didn’t have any hair, she got up and went across the room like I was contagious!” says Katie.
> “Actually it’s the other way around. Everyone is contagious to you!” says Ann Marie.
> “Oh, I know! My nieces don’t like it when I don’t wear my wig. They tell me to put my hair back on.”
>
> – socio-emotional group, TN

Although Katie’s nieces avoid her because of her perceived contagiousness, Ann Marie tries to protect Katie’s feelings by reframing the nieces’ actions in terms of their contagiousness to her.

As Goffman notes, two groups of sympathetic others exist: the stigmatized themselves and the “normals” who understand them. Sympathetic normals understand the stigmatized from viewpoint of having a stigma and the understand the consequences of their stigma. Physicians who treat cancer patients appear to be one group of sympathetic normals. A physician guest speaker at an informational group meeting substitutes a less stigmatizing term for a more stigmatizing one:

> “Impotence. You see it all over t.v. I’d rather use the term E.D. (erectile dysfunction) because it seems to have a less negative connotation,” says the doctor sipping his drink.
>
> – informational group, TN

Likewise, the same physician tries to show that cancer patients are not the only ones who suffer from erectile dysfunction:

> "An erection is nothing more than filling two cylinders with blood inside the penis. That's it. Anything that alters circulation like diabetes will interfere with an erection. It's not restricted to the few, the proud, the gray." I hear a couple of hearty laughs...
>
> – informational group, TN

Erectile dysfunction serves as a highly sensitive and important topic to men with prostate cancer. The physician reminds them that this condition can arise from a whole host of other medical conditions, thus easing the feeling of being set apart by prostate cancer.

As demonstrated above, the stigma of cancer was an infrequent topic of discussion for cancer support group members. Cancer patients who participated in the groups appeared to have a particularly strong need for information, advice and clarification. For example, they wanted advice about what to anticipate with regard to their cancers or information about how to handle an uncomfortable side effect of chemotherapy. The need for this sort of informational assistance appeared to be the predominant function of support seeking rather than coping with the various aspects of the stigma of cancer.

Additionally, perhaps support group members found that they could “pass” more readily for healthy on most occasions and thus were only “discreditable” instead of “discredited” (Goffman, 1963). Where the discredited must manage the tensions in interactions with “normals” because their stigma is more visible, the discreditable, whose stigma is less apparent, regulate the flow of information about themselves. With certain exceptions like impaired physical functioning, cancer patients in my data may have simply experienced fewer issues related to the stigma of cancer because they could hide the extent of their true condition.

### Conclusions

The purpose of this chapter has been to demonstrate how group ideology and norms guide the types of coping assistance provided by cancer support groups. In keeping with Thoits’s typology (1986), cancer patients managed others’s situations and emotions through a variety of coping assistance strategies. The exchanges between group participants illustrated a wide variety of issues subject to coping assistance techniques. Members advocated the removal or distraction from an upsetting situation when the situation itself could be manipulated. When this was not possible, they worked to reinterpret each others’ circumstances to reduce threat. If aspects of the situation could not be altered, participants manipulated each others’ emotions cognitively and behaviorally. Relabeling one anothers' emotions or changing their physiological response altered members' emotional state.

The data show how coping assistance operated to perpetuate the groups' norms and ideology. The members of cancer support groups described receiving solicited and unsolicited coping assistance from fellow members, friends and family members who could be perceived as helpful or, on occasion, unhelpful. The coping assistance offered was routinely utilized to bring a member back into line with group norms or ideology and to reassure or relabel a member's thoughts and feelings when those thoughts and feelings conflicted with the mainstream. Supportive exchanges also maintained existing ideology or norms by reinforcing or augmenting group members' ideologically appropriate thoughts and actions.

Moreover, this chapter demonstrated the limits or "margins" on the kinds of coping assistance one might hope to receive depending on the ideological or normative principle invoked. For example, a member might reasonably pursue alternative forms of healing to augment efforts to take care of oneself; however, sanctions would be applied if one supplanted conventional medicine with alternative medicine. Or, if in an effort to subscribe to the ideological principle of taking charge of their treatment, members then berated themselves for failing to recognize potential warning signs of cancer earlier. So group members reined in others' thoughts that might lead to self-blame or further distress.

The empathetic understanding central to these support groups served to increase the likelihood that group participants would seek or offer coping assistance they deemed advantageous or useful based on personal experience. Members sought out persons with whom they perceived similarity either situationally or experientially in order to assess their own situation or feelings. Comparisons with others' experiences provided standards against which individuals compared themselves favorably or unfavorably, allowing individuals to measure their performance against the group. My results show that despite the format of the support group, socio-emotional or informational, both types of groups offered both kinds of assistance. In other words, socio-emotional groups also provided informational aid and informational groups also provided emotional aid. Perhaps because both informational and socio-emotional groups tend to uphold the same kinds of ideological principles, their members exhibit similar kinds of supportive exchanges.

# CHAPTER VI

## SUMMARY AND CONCLUSIONS

I undertook this study with the primary purpose of understanding how cancer support groups might be usefully reconceptualized as subcultures. Although the conceptual meaning of subculture has been interpreted in a variety of ways by numerous researchers, the use of the term here is meant to indicate that cancer support groups contain characteristics clearly distinguishable from the dominant culture. In other words, as Wolfgang and Ferracuti (1967) argue, the designation of a group as a subculture does not necessarily confer a value judgment about that group as deviant or undesirable (p. 95). Reconceptualizing cancer support groups as subcultures permits one to focus on the distinct patterns of behavior that arise from group-generated ideology and norms. By viewing groups through a subcultural lens, one may focus analytically on the unique outlook created by the groups that combines elements of mainstream beliefs with those gained through personal experience and understanding.

My observations showed that support groups did indeed have three distinctive characteristics of a subculture: ideology, norms and coping assistance strategies. Ideology offers participants an alternative set of beliefs about cancer based on personal experience and intuitive understanding. Norms outline the range of suitable thoughts, feelings, and behaviors for the specific situation as defined by the ideology. Together ideology and norms influence the types and extent of coping assistance offered by the groups to participants in need of support. Each of these components contribute to the unique outlook cancer support groups collectively share.

What distinguishes this dissertation from previous studies of social support and cancer is the consideration of the context in which social support occurs. Researchers have typically relied upon self-report data to determine the sources, effectiveness, and extent of social support people perceived or received when facing cancer. I instead chose to observe participants in a setting expressly geared towards the provision and receipt of coping assistance in order to capture supportive transactions as they unfold organically. By observing coping assistance in a naturalistic setting, I was able to focus on the normative and ideological influences on the types of supportive strategies offered by the groups rarely studied before (see Francis, 1997).

I argue that cancer support groups adhere to five broad ideological principles: it is important to follow conventional treatment; it is important to take charge of your health; it is important to maintain a positive outlook about the future; it is important to listen to your body; and, support groups offer safe haven from the outside world. Groups believe that following conventional medical treatment offers patients the best chance of beating cancer. By enforcing this principle, members come to believe that pursuing alternative treatments not only can be risky, but also fatal. By stressing the importance of taking charge, groups expect that members will be pro-active in dealing with their doctors, gathering information, and making medical decisions. This belief is the product of members' pooling their understandings, experiences and doctor encounters through which others come to know the fallibility of the health care system and why they must take responsibility for their care. Through subscribing to the belief in keeping an optimistic outlook, groups not only keep members' spirits high, but also attract and retain members with their positive message. Clearly, if support groups only provided participants with a gloomy outlook and dire prospects, no one would want to attend.

Cancer support groups also believe that members must listen to their bodies, re-prioritizing and resting as necessary, in order to care best for themselves. Where members may hide the disturbing aspects of their appearance or their illness for the sake of others, this ideological principle dictates that the well-being of the individual overrides the concerns about others' reactions or feelings. The belief that support groups provide safe haven allows members to let their guard down without fear of repercussions. Members enforced the belief of safe haven by permitting free self-expression regardless of the topic. These five ideological principles work in tandem to offer an alternative to conventional beliefs about cancer.

These ideological principles incorporate aspects of mainstream beliefs as well those gained through personal experience and understanding to differing degrees. In other words, a group belief that appears completely mainstream on the surface is given its own unique twist by the groups. For example, the belief that cancer patients must follow conventional medicine appears conventional on the surface. However, groups appear to take the belief to the extreme by steadfastly refusing to tolerate any attempts by groups members to supplant Western medicine with seemingly reasonable alternative treatments. Likewise, members are urged to take responsibility for their care and recovery not just by deferring to their doctor's orders, but by being especially aggressive in confronting their doctors about their decisions and judgment. Groups strongly encourage their members to focus on the positive to the point of distorting the reality about the true extent of one's situation that might be terrifying if directly confronted. In these ways support groups' beliefs either conflict with the mainstream or exaggerate mainstream ideology about cancer.

The norms described in this dissertation outline the appropriate ways in which members should act, think and feel with respect to the five overarching ideological principles. Behavioral norms are socially situated rules that guide individual behavior; likewise, cognitive norms are those which govern appropriate individual thoughts about a given situation. Emotion norms regulate private feelings and outward emotional expressions. I also documented an additional set of behavior-related norms, procedural norms, that shaped how the groups functioned.

Two ideological beliefs – following conventional treatment and taking charge – directly translated into cognitive norms, guiding members how to think with regard to these two principles. The belief that it is important to listen to one's body constituted a behavioral norm directing members to reorganize their lives in order to better care for themselves. The importance of maintaining a positive outlook was enforced through both behavioral and cognitive norms, instructing members to live normally and stay involved as well as think positively. The principle of support groups as safe haven was upheld largely by emotion norms to make each other feel good, to receive sympathy and concern, and to permit venting and complaining. In keeping with the belief in the groups as a safe haven, the behavioral norm of accepting deviations in appearance permitted members to appear as they were.

The cancer support group norms described in this chapter also reflect violations of the broader normative rules at work in society. For example, group members' acknowledgment of the need to maintain a normal and thus non-threatening self-presentation for outsiders shows how external expectations shape behavior. Failure to uphold this particular mainstream appearance norm for the sake of outsiders could have potentially serious consequences for the provision of social support, if outsiders perceive a so-called “sick” appearance as too upsetting or too unsettling to be around.  It is important to note that participants themselves created their own norm to contradict this mainstream norm, and, in fact, perceived these deviations in physical appearance or functioning as normative and even expected for persons with cancer.

One the chief functions of the groups was to bring deviant thoughts and feelings back into line with the ideology of the group.  At the outset of this dissertation I had anticipated that emotional deviance would feature prominently in the groups’ discussions; however, episodes of cognitive deviance appeared with equal or greater frequency in my data.  I argued initially that the unrelenting distress caused by cancer would prompt patients to seek the support of similar others for clarification and validation.  I did not expect that support group members would demonstrate such a strong need for cognitive guidance from other cancer patients.  Members displayed a much more intense desire for information about their illness and treatment than I anticipated.  This finding suggests that perhaps by gathering information about one’s particular situation, one may be taking an important step towards improving how one might feel about that situation.

The instances of emotional deviance documented here showed that members themselves understood when they had overstepped the boundaries for appropriate private feelings or suitable emotional expression under certain circumstances.  Likewise, members in upholding the groups’ emotion norms worked to bring inappropriate feelings and displays back into line.  Group participants also demonstrated for each other how they should think about their situation, given the ideological constraints of the group.  Members seemed to tolerate and even encourage a wide-range of emotional expressions by members within the groups, although they seemed to be far less tolerant of deviant thinking about cancer.  Indeed, thoughts that violated the core ideological beliefs or the supporting norms appeared to arise with greater frequency because cognitive deviance may have been more threatening to the group’s well-being and individuals’ survival than emotional deviance.

I had anticipated that cancer as a stigmatizing condition would result in persistent emotional distress that in turn would prompt individuals to seek assistance from the support groups. I thought that joining a support group would be one response to dealing with the frustrations generated by negative interactions with broader society. I found essentially no evidence in support of my hypothesis. Members rarely made reference to coping with stigma. In group discussion, members emphasized their need for information, whether to deal with the uncertainty about what lay ahead or to exercise some control over the path of their illness. Furthermore, my data suggest that cancer patients may have fewer issues with stigma because they understood their “sick” appearance might be shocking to “normals” and often took the necessary steps to conceal their true physical condition to outsiders.

Ideology and norms together shape the coping assistance strategies members use themselves and suggest to others. In this way, the ideology gets taught to new members and reinforced among the old members, demonstrating its basic interactional nature (Francis, 1997). Coping assistance works to alter the problem or the emotional reaction to the problem by changing behavior or thoughts to reduce threat and upset or prevent potentially self-damaging behavior. Members could solicit coping assistance from one another, or they could offer unsolicited coping assistance to others in distress.

When the topic of conventional medicine arose, members offered largely cognitive assistance aimed at reinterpreting the problem (usually chemotherapy) to seem less threatening. However, when members sensed another’s profound distress around making decisions regarding treatment, they emphasized emotional support over bringing deviant beliefs back in line. Cognitive reframing of stressful circumstances and advice-giving were the types of coping assistance given with respect to the ideological principle of taking charge. In keeping with this belief, members demonstrated that by being well-informed about their condition, they positioned themselves to challenge the advice given to them, including physicians’ advice. The importance of listening to one’s body included informational assistance aimed at helping members to reorganize their lives and put their health first. They also offered each other instrumental assistance that facilitated member’s ability to take care of themselves.

By reappraising circumstances as less dire, members could help each other to maintain a positive outlook. They could also assist with an upsetting emotional state by offering themselves or similar others as comparison targets for guidance or favorable self-evaluation. With respect to the belief that support groups offer safe haven, members offered a variety of coping assistance strategies. They offered each other largely emotional support that promoted positive feeling through ventilation of frustrations, expressions of concern, and empathetic understanding. Members could also provide advice based on their own experiences about what to anticipate with respect to diagnostic, treatment, and post-treatment periods of cancer. I would also add that attending support groups in themselves serves as a coping assistance mechanism for gaining informational, instrumental and emotional support.

Coping assistance strategies intended to support one ideological principle or another at times could mutually facilitate the enforcement of more than one belief, or could violate another belief when carried too far. For example, in the spirit of taking charge, participants occasionally looked back on the time prior to their cancer diagnosis, scanning for any indications that they had put themselves at risk for getting cancer. From one perspective, this kind of vigilance may support the belief in taking responsibility for oneself and lends some support to the importance of listening to one’s body. However, enforcing these beliefs retrospectively may be seen as exacerbating one’s own stress further, violating the principle that one should focus on the positive. I argue that coping assistance efforts had its limits, depending on which ideological principle being enforced.

Further, I found evidence that empathetic understanding appeared to be an important condition for the perception of coping assistance as effective. Members looking to offer or to receive a particular type of coping assistance such as advice or emotional support searched for those in the group with whom they perceived situational or experiential similarity. Moreover, there were times when not just any kind of empathetic understanding would do. Members demonstrated that perceptions of situational and/or experiential similarity could be quite exacting and that sharing a diagnosis in common was not necessarily sufficient.

Interestingly, in a group dealing with a potentially life threatening disease, the topic of death arose relatively infrequently. As mentioned in the chapter on norms, group members might discuss death as a matter of course in making plans for one’s eventual demise that any responsible person, ill or well, might do. Occasionally, the use of “tumor humor” helped to offset threatening feelings that arose when the topic was discussed, but overall members appeared loathe to discuss death under any other circumstances. They appeared to be more determined to keep the focus of discussion on matters pertaining to their recovery and returning to their lives as usual.

### Limitations

Although I believe the research design used in this study was the method best suited to answering the question of whether or in what ways cancer support groups may be seen as subcultures and to describing the ideological principles, norms, and coping assistance strategies used by the groups, clearly participant observation has its limitations. Most obviously, a major limitation of this study is that it was restricted to the cancer support groups to which I had access.

Group facilitators, both lay and professional, served as gatekeepers for their support groups. I simply could not gain access to support groups to ask for their participation directly. Thus, it was left up to the facilitators' discretion whether or not they would ask their support group if I could participate. I did not always know the reasons why facilitators did not permit me to observe their groups. When a reason was provided, facilitators generally expressed concern for the preserving the group as a safe haven for the participants.

The overall number of groups I was able to observe was admittedly low - six in total. However, there was a practical consideration to observing only a small number of groups. Because I was recording notes mentally rather than with the use of a tape recorder, I needed time to jot down a quick set of notes when I arrived home and then time to transcribe the meeting with greater detail in its entirety. Given the time-consuming demands of taking mental notes and subsequently writing fieldnotes, I could only follow a small number of groups over time. Had I used longitudinal participant observation to follow a larger number of groups, this task would have been far more difficult and demanding. By focusing only on six support groups, I was able to obtain highly detailed longitudinal data because I observed them multiple times over the course of a year.

Because I relied on participant observation exclusively, I was not able to interview participants post-group to get their private thoughts on the exchanges within the group. I had to rely on my own perception of how members were thinking and feeling without knowing how members may have truly thought and felt. By classifying coping assistance strategies as effective or ineffective, I relied on my own interpretation of body language and personal statements made by the members mid-group. I cannot determine definitively whether or not outwardly the affirmative displays or remarks I observed actually reflected genuine feeling or not. Members may have engaged in “surface acting,” the means by which we deceive others about how we really feel, but not ourselves (Hochschild, 1983). Thus, these data cannot be used to assess adequately the perceptions of support group effectiveness without access to the interior worlds of the members.

In addition to these concerns about the underlying thoughts and feelings of the participants, my sample tended to be disproportionately white. In my data, I had one African-American woman who left her group fairly early on during my period of observation. The only other non-white member who attended the groups was a Filipino man. It would be useful to know if other support groups with differing racial and ethnic compositions would create different kinds of ideological beliefs, norms and coping assistance strategies from those I captured here.

Aside from being disproportionately white, the participants in Florida tended to be persons roughly in their 60s or older. The area in Florida in which I could gain access to support groups happened to be a popular retirement destination for people moving from the Northeast or Midwest. The average age at which a person receives a cancer diagnosis is 60, so group members in all six groups tended to be skewed older rather than younger overall. Thus, older age is not necessarily a limitation of my data, but groups comprised of younger cancer patients might have different cultures.

My attempt at sampling single sex groups had its limitations as well. The “all male” support group I observed consisted of male cancer patients often accompanied by their wives or other family members. My attempt at attending an exclusively male support group proved to be unsuccessful because of my gender. Therefore, I do not know the ways in which the male group I observed might vary from one in which women excluded.

Levy (1976) attempted to categorize the types, psychological processes, and effectiveness of self-help groups based in part on his observation of groups. Leadership could be strictly professional, strictly peer led, or a combination of the two. As Levy noted in his own attempt to create a support group typology, leadership was often shared and at times roles were impossible to discern. Leaders in my study may have controlled the overall structure of the group (as outlined in the procedural norms section), but they deferred to the group as to the content. Certainly cancer support groups with professional facilitators who control both the structure and the content exist, but are not captured by my data. It may be useful to contrast groups with a therapeutic perspective led by professionals with those with an experiential perspective, as mine were for alternative subcultural ideology, norms, and coping strategies.

I tried to maximize variability in the groups using the leadership structure described above as well as function (socio-emotional vs. informational) to compensate for the small sampling of groups I had. Although groups ostensibly served one function or another, my data showed that both types of groups met both types of functions. My failure to observe a strictly informational or socio-emotional group makes it difficult to draw any real distinctions about the effectiveness of one kind of group over another. I speculated that the combination of group functions may be the by-product of shared ideological principles.

### Future Concerns

The theoretical implications of my findings are more suggestive than definitive at this point. Research on support groups themselves has been limited to evaluations of the groups as psycho-social interventions to improve the members' quality of life, or, on occasion, to maximize cost-effectiveness by counseling groups instead of individuals (Helgeson et al., 2001). This psycho-social intervention approach generally uses quantitatively measurable outcome variables such as knowledge about treatment, coping, affective state, and physical status to determine the groups' effect on members' overall adjustment to a cancer diagnosis. As Helgeson and Cohen (1996) suggest, researchers are still unclear exactly which elements of group interventions provide the maximum benefit to the participant.

One implication of my study is that future theorists may benefit from examining the *process* through which social support occurs in a naturalistic setting. I attempted to identify conditions under which different kinds of social support may be offered and which types of social support may be found to be effective (or ineffective) given those conditions. Existing research has yet to examine coping assistance strategies using actual transactions between the sufferers and support providers, or the extent to which those strategies may be influenced by other factors such as cancer stage, gender or ethnicity/race. Because empathetic understanding from similar others appears to be a key to support groups' effectiveness, future research needs to be conducted on empathetic understanding to determine which types of member similarity are most conducive to the provision of effective coping assistance.

There exists little evidence about the processes or techniques by which others participate in the transformation of deviant emotional or cognitive experiences (Thoits, 1990). In fact, we know very little about what circumstances prompt others to sanction deviant feelings, displays or cognitions, much less how or why otherwise well-socialized actors come to engage in emotional or cognitive deviance in the first place. Observations of the process of redefining feelings or thoughts can help inform our understanding of group processes in general, such as the formation and enforcement of ideology and norms.

Certainly not all people with cancer experience extreme distress and anxiety that requires them to search for support outside of family and friends. Some may experience only a transient period of anxiety while others remain in a heightened state of distress. Interview data could supply more information about why cancer patients seek or do not seek the assistance of a support group. What are the distinguishing characteristics of those who do not need the help of a support group versus those who do? How do group "refusers" perceive support groups? One study found that refusers responded to the invitation to join a counseling program as an insult, or, worse, a negative commentary on their mental state (Worden and Wieisman, 1980). What might be done to overcome the misgivings of persons who could benefit from a support group, but who refuse to attend?

As mentioned earlier, the participants in the support group were overwhelmingly white and at a minimum had the physical capacity to attend the group meetings. It would be important to know the relevant cultural factors that discourage or impede persons of other ethnicities and races from attending cancer support groups. Clearly the problems created by cancer are not any more prevalent in whites or the ambulatory. Overall participation in cancer support groups is quite low relative to the number of people diagnosed with and treated for cancer. What are the barriers to seeking the help of a support group for cancer patients who could benefit from their assistance? What are the prevailing preconceptions (or misconceptions) about support groups?

The ever-changing demands of cancer as one moves through the sequence of the illness – diagnosis, surgery, treatment, waiting – are particularly stressful and require guidance and information about what to expect next. Future research needs to show how the demands for certain kinds of coping assistance shift as one progresses through this illness trajectory. At what point in the course of the cancer experience does a support group begin to relieve the anxieties and concerns of the member? In particular, as cancer patients live longer, they may require a particular kind of coping assistance in the post-treatment period that differs from earlier periods.

By demonstrating that cancer support groups do function as subcultures, I show how these groups have distinctive elements that contribute to a unique outlook on the cancer experience for their members. Thus, one of the reasons why it is important to examine support groups as subcultures is because it focuses the researchers' attention explicitly on ideology, norms, and exchanges of assistance and sanctions within groups that normally are overlooked, but which clearly have significant effects on members' thoughts, feelings, and behaviors. I would argue that the reconceptualization of support groups as subcultures may also be fruitfully applied to other sorts of groups addressing issues such as bereavement, drug addition, or gay parenthood in order to understand how they may offer their own particular kinds of ideology and coping assistance. The reexamination of different types of groups also offers insight into the normative experience of a particular problem or condition from the sufferer's perspective. We may come to understand how thoughts, emotions and behaviors may be seen as deviant by the mainstream and how they may be reinterpreted by support group members.

Finally, Wuthnow (1994) points out that the "small group" movement grew dramatically in the 1980s and 1990s to encompass an ever-expanding range of issues for which people may seek support. He suggests that because so many groups exist, individuals may "shop around" for the best fit and then drop out when their satisfaction wanes (p. 141, 1994). The emphasis on shopping suggests that individuals are more interested in their own self-satisfaction than any enduring sense of commitment to one group (1994). The fluidity with which individuals move in and out of groups suggests that ties to others in society may be weakened or broken with the same ease (p. 6, 1994).

I disagree with Wuthnow's characterization that small groups or support groups are part of a larger movement that stresses the needs of individual at the expense of close attachments to family or community. I would argue that support groups help individuals maintain their relationships with other people by supplementing the support not found naturally in one's existing informal support network. As my data show, they offer participants a safe haven for venting and complaining as well as receiving effective coping assistance. Support groups offer an alternative source of support that individuals can turn to without fear of overburdening, frightening, or distancing significant others who may offer other kinds of necessary support. In this way, support groups serve to sustain, not supplant, relationships with others by allowing the individual to address individual needs for support without disrupting relationships with friends and family. In contrast to Wuthnow's argument, support groups not only sustain the wider community but offer their own community with its own unique understandings, ties, and forms of assistance .

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