Mediating Disruption

This is the reason why I show it [a scrapbook] to you. It’s easier to understand why I am here and how I became an old woman. This [picture] is a press conference in Budapest. And this is at the Parliament, the last time. My husband didn’t want to leave Hungary. People lose their identity [when they leave]. But they came to arrest him, and we escaped. We hid in a chicken coop for two days. We decided we have to come [to the United States]. They put us in a van and drove us to a safe house that hid a Jewish family in World War II. Then we went through the border patrols. The car had an American sign on it. Russian soldiers everywhere. In eight days we landed in New York. It was the longest ride in my whole life. I woke up only in America, to know that we are not at home.

I lived two lives. It’s two different lives. And sometimes they are fighting with each other. . . . And now, finally, I can go back to visit. And if I want to meet with my family, I have to go to the cemetery.

eighty-two-year-old refugee
from the 1956 Hungarian Revolution
At eighty-two, Mrs. Marya Zabor, a refugee of the Hungarian Revolution, is painting her personal history, the canvas of her life. Small and fragile looking, her expressive hands move in the air as she moves from one picture to the next, in a continuous process of life reconstruction. She cannot afford to buy canvas, so she improvises; she paints on scraps of wood and pieces of cardboard. The walls of her single room are completely covered with her paintings. They are scenes from her life: some are dreams, some are memories. When she is not painting, she is inspecting her work for clues to self-knowledge. While she spends her days alone, painting, her mind is busy as she continuously sorts out the past and tries to find commonalities between it and the present. There are few.

Life in America, it’s a million persons different than in Europe and certainly different than in a smaller country like Hungary. And this is double work to get used to it and to accept it.

I tried to clarify what she meant: “You mean to find some common ground or something that you have in common with others?”

Yes, that’s right. And even so, I know many Hungarians in New York and here. Some of them died, some of them went back to Hungary. But the people are changed. They’re not the same. We used to say, “When they put their feet on the ground of America, they are changing.” They are lying so much. Everything I can tolerate. Just not to lie. If you met someone after the ‘56, you know, he wasn’t a soldier, he was a lieutenant; it wasn’t a person who served in a store, it was a manufacturer. And if it helps them, that’s one thing. It’s their problem. But I can’t stand it. Because I came from the same place, and I know who they really were.

I’m not blaming them, I’m blaming myself that I’m not able to try to get closer to them by changing my viewpoint of what is a whole life.

Mrs. Zabor’s story highlights the major elements of a disrupted life—the disruption itself, a period of limbo, and a period of life reorganization. As she talks about her identity in the aftermath of change, other essential elements emerge that give the story depth and context. On the eve of the disruption, she was a member of the Hungarian intelligentsia, married to a man with great political power and considerable wealth. Today she is a widow who lives in poverty in a single room.
Nothing remains of her former life except a scrapbook, a couple of pieces of antique furniture, and her memories, translated onto scraps of paper and wood.

Mrs. Zabor’s attempts to rediscover her whole life by painting scenes from it are manifestations of her intense, lifelong preoccupation with her sense of self. In reflecting on this preoccupation, she observes that she has developed a “viewpoint of what is a whole life.” In her view, other refugees have lost their identities by portraying themselves as they would like to be seen rather than as they really are. Her story shows how disruption can bring about renewed efforts at self-discovery and highlight concerns about how the self is portrayed to others.

Throughout her narrative, Mrs. Zabor underscores differences: differences between Hungary and the United States, between the known and the unknown, between a picture of herself in a scrapbook and the picture of herself as an old woman. She tries to reconcile these differences, to create continuity, through metaphor, through words and art, an alternative system of metaphor in itself. She metaphorically captures the period of limbo she experienced during her eight-day flight from Hungary to the United States when she portrays that journey as “the longest ride in my whole life.” Mrs. Zabor juxtaposes two metaphors—flight and fight—to illustrate the conflict between the two lives that she has lived, two lives that are “sometimes fighting with each other.” In the flight metaphor, she depicts danger through a series of motifs: near arrest, escape, concealment in a chicken coop and in a safe house left over from another war, flight from soldiers and border patrols. Through this metaphor runs another metaphor: the car with an American sign on it—the car that transports her into another life—represents safety. The metaphorical fight is an internal one, a fight within the self. She draws attention to her realization of the profound changes at the end of the journey when she says “I woke up only in America, to know that we are not at home.” Through metaphor, she thus elicits a haunting image of tension between the two lives, the one before the revolution and the other after, an image that is unlikely to dissipate.

Death also appears in Mrs. Zabor’s story—the metaphorical death of the old way of life as well as actual deaths. Despite her efforts to unite
past and present through her art work, the harsh truth remains, “If I want to meet with my family, I have to go to the cemetery.”

Mrs. Zabor has condensed half a lifetime of disruption into a few powerful metaphors that convey the essential elements of the disruption in which she was caught: the enormous wrench of revolution disrupting her life; the period of limbo, of liminality, during which she waits to learn the outcome of her forced flight; and the laborious, forty-year effort to create a sense of continuity in the face of unwanted and irrevocable change. Her narrative reproduces the metaphors in her paintings, and she uses these metaphors to mediate the disruption to her life.

**CREATING CONTINUITY**

In this book I examine the process by which people attempt to create continuity after an unexpected disruption to life. People’s efforts to create linkages with the past during times of disruptive changes—whether societal, such as those caused by a revolution, or individual, such as the onset of illness—have been readily observed. People maintain continuity with the past amid the facts of change by interpreting current events so that they are understood as part of tradition. The ongoing interpretation of events and experiences enables people to make sense of their personal worlds; and a knowable world provides a framework for understanding major events as well as everyday experiences. A sense of continuity is captured in ordinary routines of daily life, the mundane and comforting sameness of repetitive activities, such as drinking a cup of coffee with the morning newspaper. These activities give structure and logic to people’s lives.

In all societies, the course of life is structured by expectations about each phase of life, and meaning is assigned to specific life events and the roles that accompany them. When expectations about the course of life are not met, people experience inner chaos and disruption. Such disruptions represent loss of the future. Restoring order to life necessitates reworking understandings of the self and the world, redefining the disruption and life itself.
The effort to create order is, in essence, what anthropologists study. Although the ways in which people strive to create order out of chaos and thereby render life meaningful have been an enduring focus of anthropological study, the majority of anthropological work has not focused specifically on disruptions to life. When disruptions have been observed in the course of research, or “fieldwork,” as it is referred to in anthropology, they have served to give point and form to anthropological observations of daily life by throwing cultural phenomena into relief. Some argue that a concept of culture must include those moments in social life when what is normal and habitual is disrupted and gives way to a new realm of possibilities. The preoccupation with culture as a monolithic entity, which prevailed in the preceding era in anthropology, obscured the potential to understand what happens when things go wrong, when events fall outside of people’s experiences of life and their expectations about it.

Although continuity is apparently a human need and a universal expectation across cultures, continuity has a culture-specific shape. Western ideas about the course of life emphasize linearity. Metaphoric images of development and progress include gain and loss. The life span is seen as hierarchical, and aging as a “hill.” The underlying assumption that development occurs over the entire course of life has its roots in long-standing theories of evolution that inform notions of order and progress in the West. Western thought is organized to make sense of individual lives as orderly projects, but when this concept of the life course is translated into experiences of individual people, there is a great deal of slippage because real lives are more unpredictable than the cultural ideal.

Anthropologists studying U.S. society have observed the need to preserve or reconstruct some semblance of continuity in the wake of disruptions to life. Distress seems to be a major organizing factor in the way life stories are told in the United States; these stories often focus on adversity and on the means for resolving unexpected disruptions among previously ordered events. The likely reasons for this focus are the aforementioned emphasis in the West, particularly in the United States, on the linear, orderly unfolding of life and the emphasis on the individual, the self, in relation to society.
The way that order and chaos are thought of in the West has recently begun to change. Chaos has been negatively valued in the Western tradition because of the predominance of binary logic: if order is good, chaos must be bad because it is viewed as the opposite of order.\textsuperscript{12} This attitude toward chaos has now begun to shift with the advent of chaos theory. Chaos theory suggests that deep structures of order are hidden within the unpredictability of chaotic systems, that chaotic systems exhibit orderly disorder rather than true randomness. The advent of chaos theory is part of a major paradigm shift, a shift from a Newtonian paradigm emphasizing predictability and linearity to a paradigm of “chaotics.”\textsuperscript{13} This latter paradigm celebrates unpredictability and nonlinearity and sees both as sources of new information.\textsuperscript{14}

It takes time for new ways of thinking to pervade daily life, especially when the old paradigm has been particularly pervasive. Western understandings of order continue to revolve around linearity, and this book consciously reflects that tendency. We will get brief glimpses of the paradigm shift, but, for the most part, we will see just how deeply embedded is the traditional Western paradigm of predictability and order in people’s lives. We will see how people organize stories of disruption into linear accounts of chaos that gradually turns to order.

The stories of disruption in this book thus capture a transitional moment in time. The future may hold a greater engagement with, and subsequent comfort with, notions of chaos, but we are not yet seeing people express that sentiment. Instead, people continue to draw on traditional cultural understandings of order and chaos in interpreting the disruptions in their lives. Because people are gradually integrating scientific models into their understanding of their everyday world, it is likely that with the passage of time the chaotics paradigm will take its place along with other explanations for why things go awry in life. We will see a few examples of this phenomenon among people who use biomedical technologies and consequently wrestle with disparities between old and new ways of seeing the world.

My studies of disruption to life are situated in a specific anthropological perspective: that each culture has its own expected “cultural life course.” The course of life can be viewed as a cultural unit and a power-
ful collective symbol. As a collectively shared image, the cultural life course may, through metaphor, provide people with images and motivations that guide their lives as members of society and as individuals. For example, the “journey of life” metaphor is a root, or organizing, metaphor. European representations of the life spiral portray another cultural conception of the life course. Although the life course was traditionally portrayed as a life wheel, life bridge, or staircase, this iconography was allegorical and linked life stages to the dance of death, serving as a reminder that death could strike at any time. These portrayals, which date to the fifteenth century, referred to the basic insecurity of life. In the nineteenth century, these portrayals, in their secularized form, lost their reference to the dance of death, and the individualized life course emerged as the basic code for constructing experience in Western societies. The contemporary Western conception of the life course as predictable, knowable, and continuous is thus a relatively recent phenomenon.

I view disruption as a part of the human condition. After analyzing hundreds of stories of people whose lives have been disrupted, I have come to see responses to disruption as cultural responses to change. These efforts to create continuity after a disruption emerge as a complex cultural process. When I began writing this book, I did not intend it to be primarily an analysis of U.S. culture; yet that is what it has become. The examination of disrupted lives and the efforts people make to regain a sense of continuity necessarily entails a close look at the cultural context in which disruption occurs and, ultimately, at those cultural dynamics that are at the root of the disruption. In this book, I explore this process through an examination of how disruption is both embodied and portrayed by people in the United States who have undergone a variety of disruptions to their lives. The strength of the ideal of continuity and its pervasiveness suggest that in the United States disruptions to life may seem all the more abrupt because of the tendency to view life as a predictable, continuous flow. Expectations about continuity permeate responses to disruption as well as efforts to create continuity after disruption has occurred.

The study of disruption and people's efforts to create continuity does
more, however, than simply unpack a pervasive assumption that there is continuity in life. Studying disruption enables us to examine the well-springs of many core tenets of U.S. society and to explore how deeply those core tenets are embedded in the cultural contours of people’s lives. These tasks are part of what I undertake in this book.

FROM LIVING WITH DISRUPTION TO STUDYING DISRUPTION

It has become commonplace for anthropologists to link themselves personally to their fieldwork, and this approach represents a shift from the approach of the previous era, in which I was trained, when “objectivity” was the primary goal of the social sciences. Despite this emphasis, I knew that my personal experience was at the core of my intellectual interest in disruption. My studies of disruption in people’s lives have been fueled by my lifelong efforts to create a sense of continuity in my own life. I wanted to understand the process undergone by people who experience disruption so that I could apply what I learned to better cope with disruption in my own life.

My childhood was punctuated by a series of disruptions, some subtle yet profound, others seemingly cataclysmic. As I was growing up, my life seemed to be a sea of unforeseen changes, disruption, and uncertainty studded with islands of stability, brief periods in which life went on as normal. I struggled to stay afloat.

These disruptions were all the more potent because of the sociocultural and historical context in which they occurred. I grew up in the years of flux and change following World War II in an urban San Francisco neighborhood trying to cling steadfastly to its Jewish and Italian roots. My childhood world was a tiny island surrounded by a bustling Army base and two neighborhoods that were undergoing major population changes. Before the war, one of these neighborhoods had been populated by African Americans, Japanese Americans, and Jewish and Italian immigrants. World War II brought the migration of black southerners to work in the shipyards of California. Many Japanese Americans who
had lived in rural California before their internment in concentration camps during the war did not return to their land: they came to San Francisco instead. The other neighborhood was one in which generations of Chinese Americans and Italian Americans had lived. Suddenly, in the wake the war and the Communist Revolution in China, that neighborhood became a mecca for thousands of refugees from Asia, primarily China.

Both neighborhoods filled up and overflowed their boundaries, pressing against the small, predominantly white, middle-class neighborhood in which I lived. Children of all colors filled the schools, bringing their cultural backgrounds with them. Their parents, who often spoke no English, filled the streets. No one ever said in front of me, “We must keep them out,” but people in my neighborhood struggled to maintain a wall against these outsiders. A strong undertow pulled people in this postage stamp–sized neighborhood toward the staid, predictable patterns of the past.

I was the outsider inside the gates of my still white neighborhood. I was raised primarily by my grandparents, who as Christian Scientists were not even in the Protestant mainstream. Not only did they not go to doctors, but my grandmother was a faith healer, or, to use the parlance of Christian Science, a practitioner. I stood out in this neighborhood where every other family was Jewish or Catholic. I left the classroom when the science lesson started. I didn’t go to mass or temple with my family. I didn’t participate in the ethnic celebrations that were so much a part of the life of this community.

As I became an adult, the disruptions in my life became harder to ignore. At ten, I developed allergies and asthma. Unchecked by medical treatment, these conditions ruled my life. My eyelids would swell almost completely shut in the spring with the arrival of the pollen carried by seasonal winds; my lungs were congested every winter from colds and flu. I was absent from school often. When there, I was a liability in team sports: I ran slowly and wheezed audibly. I felt disfigured and grotesque.

When I was thirteen, a school counselor advised me to switch from a college preparatory track to a business track. My schoolmates all planned to go to college. Why had I been singled out as being different from
them? College had always been my goal, and it was hard to let go of this lifelong expectation. I felt the sustaining dream of my short life begin to dissipate.

When I was fourteen, my grandfather died at the age of eighty-eight. He had hung on for over a year from the time his health had started to fail, and he died the day after I graduated from junior high school. I was so angry at this wholesale desertion when I needed him that no stranger would have recognized my response as grief; I was in a rage. He had been my pal. He taught me to read, first with blocks, then with newspapers. He walked the dog with me daily, took me on his newspaper route, cooked me truly inedible food, and bored me with baseball scores. He was good company. His going left a yawning, cavernous void.

I felt pushed out by society, disowned. I became more obviously marginal than I had been before. I became, for a brief time, an outlaw. I looked tough. I dressed mostly in black. I affected detachment, even callousness. Inside I was a mess. I practically lived on a street corner that was the turf of a “car club,” a gang that stole cars. After being taken to the local juvenile detention center because of the company I kept, I decided being an outlaw was dangerous. I went to work at sixteen, which, for me, marked the full transition to adulthood.

I eventually began taking college courses while working full-time. I then went to work in an academic setting in which I worked with anthropologists as well as others in the social and health sciences. I discovered my niche in anthropology, where marginality was not only tolerated but accepted. Indeed, the abundance of books and papers on themes of marginality and being an outsider induced me to persist in my studies. Even more compelling was the affirmation of my identity I experienced each time I did fieldwork. My first fieldwork was with people who lived on the street and teenagers who had been labeled as delinquent. I instinctively started as an anthropologist where I had left off as an adolescent.

Although turmoil is often part of growing up, I attributed mine solely to the disruptions I had experienced. The staccato pattern of disruption, change, and return to normalcy I experienced in childhood forged my identity as an outsider. The search for answers to my seemingly aberrant life experience eventually made its way into my research. Over and
over I asked how others responded to disruption, how it affected their identity, and how they viewed themselves and their lives when stability returned.

I tell my own story here not only because it has shaped my work but also for several other reasons. First, my story encapsulates many of the dimensions of disruption that appear in the other stories in this book. Specifically, it illustrates different contexts for continuity and discontinuity—family, class and ethnic background, and society more generally—and how those contexts shape people’s experiences of disruption and continuity. For example, the family may diminish sense of disruption in some ways, as my grandfather’s presence did in my childhood, and yet exacerbate it in other ways, as his death subsequently did.

Second, my story, like all of those in this book, is one of embodied distress. I felt the chaos of disruption at a visceral, bodily level long before my chronic illness—asthma—began to emerge when I was ten. I listened to my body continuously as I tried to monitor symptoms such as wheezing and swollen eyes that identified me as “sick.” My struggles to breathe left indelible memories that were embodied in my subsequent actions. My bodily response to symptoms of asthma is informed by these memories even today.

I have omitted much of that distress from my account, however, because it resurrects old fears whenever I dwell on it. Moreover, the expression of distress is not culturally sanctioned in the United States. In the United States, there is an underlying ideology, born of Puritan beginnings, that values communication through mental rather than bodily activity, that values thinking more highly than feeling. Bodily and emotional expression is suppressed. Indeed, the lack of acknowledgment of embodied distress heightens the difficulty people have in giving voice to bodily disruptions; embodied distress may be difficult to access through language and may remain muted and unarticulated. At least when I was growing up, “toughing it out” was expected. Those cultural constraints make the distress I experienced difficult to articulate even now, and the validity of embodied distress is an issue that others in this book struggle with as well.

Third, I tell my story because it contains certain elements of narratives
of disruption that appear in other stories in this book. Narratives, my
own included, arise out of a desire to have life display coherence, integ-
rity, fullness, and closure.23 I can analyze my own narrative most easily
simply because it is my own; I have told it to myself many times over the
years. In the process, I have reshaped it so that it gives a sense of coher-
ence to my life. Of course, I have not told all of it. Some parts of my story
are omitted because they seem less directly related to the “story line.”
During my formative years, I was not aware that I was reshaping events
to lend my life coherence; it is only recently, since I began this book, that
I have seen how my own story fits this narrative convention.24

The plot of my story is something on the order of “disrupted life made
good.” The story thus has a moral authority similar to that of other sto-
ries of disruption that will be told in these pages. Indeed, the stories in
this book speak directly to cultural notions in the United States of order
and normalcy. Moral authority is embedded in a specific social reality,
and the portrayal of a personal world in story form is necessary to the
establishment of that authority.25 The development of people’s narratives
of disruption is, preeminently, a cultural process.

THE DISTRESSED BODY

How are body and self affected by disruption? Order begins with the
body.26 That is, our understanding of ourselves and the world begins
with our reliance on the orderly functioning of our bodies. This bodi-
ly knowledge informs what we do and say in the course of daily life. In
addition, we carry our histories with us into the present through our
bodies. The past is “sedimented” in the body; that is, it is embodied.27 In
order to examine the full range of the effects of disruption on people’s
lives, I start with bodily experience.28

To explain what I mean more thoroughly, I will use the example of
the person who has asthma because I have already alluded to my own
struggles with asthma and because doing so provides a concrete example
of bodily distress.29 Breathing is one of the body’s most essential acts, and
the ability to breathe is taken for granted.30 People usually breathe with-
out thinking, but when breathing becomes difficult, they become self-consciously aware of their bodies, that is, of being a body. People who have asthma perennially “listen” to their bodies, anticipating as well as monitoring the symptoms of the illness, wheezing or shortness of breath. Bodily experience thus encompasses the past, the present, and the anticipated future.

The body is the medium through which people experience their cultural world, and bodily experience can reflect the culture in which it occurs. Breathing is a process that is not just physiological but also cultural. That is, when people with asthma listen for symptoms, they are engaging in a process that is culturally informed. Cultural attitudes in the United States that value stoicism in the management of illness and individual responsibility for health inevitably affect the nature of embodied distress caused by asthma. People in the United States deal with their asthma symptoms in ways that reflect these cultural attitudes; for example, they may ignore, diminish, or hide symptoms, use specific kinds of folk remedies to control symptoms, and delay seeking treatment. An emphasis on bodily experience thus informs an understanding of people’s activities and practices of everyday life.

Our bodies, as sources of moral and political knowledge, are capable of generating categories of social analysis, a phenomenon I will try to demonstrate in this book. The body can be said to produce culture. People are able to ground their resistance to the power of cultural norms in bodily experience. For example, a person with asthma may resist going to an emergency room (the recommended biomedical course of action for acute episodes of asthma) because they fear they will not receive appropriate treatment, but their resistance is tempered by their bodily knowledge: they listen to their bodies in deciding whether care is necessary. Failure to listen for symptoms, or to gauge them accurately, may have serious and even fatal medical consequences. We will see in the examples in this book that bodily knowledge informs action, including resistance to the status quo.

Bodily experience is not restricted to individuals or small groups of people but encompasses large social collectivities. Sharing experiences of embodied distress in asthma support groups, for example, may not
only lead to greater bodily attention but also facilitate social action. When we view embodied experience of people in social groups, we gain insights about cultural phenomena because doing so gives us a window on a place where people and social institutions intersect, embodied experience in communal life.

In this book, I try to maintain a balance between explicit descriptions of the bodily experiences that people have and the stories that capture those experiences; it is not an easy task, however. At times I emphasize the role of narrative in people's articulation and understanding of disruption simply because it is more difficult to portray the embodied distress that generates such narratives. It is not my intention, however, to divide them into separate realms. Instead, I want to show how, together, they make up a whole. Narrative is a conduit for emotion and a means through which embodied distress is expressed. Language gives access to a world of experience insofar as experience is brought to language.

Nevertheless, narrative cannot completely capture the expression of emotion. Although there are other media, as illustrated by Mrs. Zabor's use of art as well as narrative to address her disrupted life, narrative is the primary expressive form for the mediation of disruption. Mrs. Zabor told her story to me with considerable intensity and, occasionally, extreme agitation. She showed me photographs from newspapers, mute testimonies to her former life. She visited her various paintings hanging on the walls, sometimes just looking at them, sometimes talking about them. She paced back and forth, she looked out the single window of her room, she cried. It is difficult to portray the kaleidoscope of emotion with which she conveyed her story or the embodied nature of its expression. Because narrative can be captured by a tape recorder and transcribed onto a printed page, however, it is through narratives that we gain access to embodied distress.

Bodily practices enact the past and, hence, embody cultural memory. Narrative, as the performance of bodily experience, can therefore be seen as practice. Such performances constitute action. People project images of themselves and the world to their audiences through performance, as Mrs. Zabor did. In this book those images are projected through narrative.
WRESTLING WITH NORMALCY

I have found that people consciously wrestle with some cultural ethos that is at odds with their life situation. This is particularly true when life circumstances do not fit with cultural ideas about what constitutes normalcy. We will look at the disjunction, as it is portrayed by people in the throes of disruption, between embodied distress and cultural expectations about order. We will also see how people’s notions of order change as they attempt to come to grips with disruption to their lives. Efforts to create coherence and provide closure to situations that are at odds with their notions of order are shaped by complex cultural dynamics.

Narratives of disruption are people’s efforts to integrate disruption and its aftermath with prevailing cultural sentiments. People define normalcy in terms of particular cultural images that have salience for them. From a phenomenological perspective, people themselves generate categories of normalcy, although they may later take issue with those categories when they no longer fit with life experience. Depending on the nature of the disruption, various cultural ideals of, for example, health, womanhood, manhood, parenthood, and the aging process emerge.

When we talk about disruption to life, we are also talking about stability, which is the flip side of disruption. Stability, however it is individually defined, has cultural contours. Studies of disrupted lives afford an opportunity to examine out-of-the-ordinary life experiences for what they can tell us about cultural constructs that are taken for granted. Stories of disruption in the United States reveal ideals about order and normalcy, but these ideals are just that, ideals; they do not necessarily reflect people’s experience.

When I began my ethnographic studies, and, indeed, even when I began this book, I did not foresee the force with which certain cultural tenets concerning normalcy in the United States would dominate people’s stories or the great extent to which they would be used by people to make sense of disruption. What is most striking about the portrait of the issues that emerge when people wrestle with disruption is that in the United States core beliefs persist despite ongoing social change. Al-
though ongoing social change may affect particular cultural norms and values, the sum of those values still articulates the cultural ethos that is characteristic of the United States. To be sure, individuals vary in their interpretations of normalcy. We will explore these variations—by ethnicity, gender, class, and age—as well as similarities that persist despite such heterogeneity. The juxtaposition of disruption, and embodied distress in particular, against cultural discourses on normalcy both highlights specific kinds of disruption and throws cultural phenomena into relief so that disparities become more visible.

People strive to be normal; however, the realities of life are very different from the ideal. People have compelling concerns and precious stakes to defend; and although they would be “quite helpless without the power of cultural templates to guide and sustain them,” they live their lives uniquely.\(^{46}\) In other words, events occur continuously that do not fit with a vision of how life should be, and when they do they affect people’s individualized views of the world.\(^{47}\)

Stories of disruption are, by definition, stories of difference. Disruption makes an individual feel different from others and can render social relationships uncomfortable and cumbersome.\(^{48}\) The narratives in this book repeatedly attest to the emotional pain that difference causes and to the struggle to reduce or eliminate that sense of difference from others. Regardless of the phase of life they are in and the nature of the disruption, the people in this book view themselves as being at odds with what others—and they themselves—view as normal for their gender, age, and circumstances. They thus come into conflict with the social order as they understand it. They see themselves as marginal and may define themselves in terms of difference rather than normalcy.\(^{49}\) The stories in this book show the conflict between the desire for normalcy and the acknowledgment of difference being enacted over and over again.

Rational determinism, a dominant cultural ethos in the United States, shapes cultural discourses on normalcy,\(^{50}\) a number of which, such as the discourse on the family, the discourses on womanhood and manhood, the discourse on the self, and the discourse on aging, I discuss in this book. These discourses and others I allude to have one thing in common: they are all moral discourses. That is, they reflect dominant ideologies
about how life should be lived. The news media’s routine analysis of national news readily reveals how deeply these discourses are embedded, as well as one way in which they are continuously reinforced.

People’s narratives of disruption are moral accounts of their lives. That is, the narratives reflect people’s interpretations of these moral ideologies and their efforts to live up to them. Narratives can serve as moralizing judgments. A moralizing impulse is present in all narrative accounts; there is no other way that one’s reality can be endowed with so much meaning.⁵¹ In this book, the discourses people focus on highlight their divergence from normalcy, which thrusts them into the experience of otherness and thus requires a moralizing antidote to mediate the experience of becoming the other. Their stories have a moral authority that derives not only from invoking discourses on normalcy but also from demonstrating how attempts to live up to expectations about normalcy often fail despite protracted efforts.

By mapping culture, moral discourses help people to make sense of their world. Inability to live out moral discourses forces people to tease apart the different dimensions of phenomena they previously took for granted. People’s narratives reflect the struggle to rethink those discourses after disruption to encompass their own experience. We will see people examining discourses on normalcy to find ways to fit their disparities into society’s expectations.

Although the narratives in this book often express a longing for normalcy, they are also narratives of resistance to the status quo.⁵² Examining the tensions that surround efforts to restore normalcy enables us to understand better how resistance develops. Although I say little directly about politics in this book, the narrators say a great deal. Indeed, narrative is always political because people choose which narrative to tell.⁵³ Although we will read narratives that muse about the possibilities in stream-of-consciousness fashion, we will also examine narratives that take a particular stance toward issues of normalcy and difference. Statements that say this is who I am or am not, statements that question the status quo, and statements that self-consciously proclaim some sort of difference are all statements of resistance. Resistance to the status quo can also be seen in descriptions of empowerment through community,
for example, descriptions of participation in self-help groups, specific ethnic communities, religious organizations or in indigenous health-related activities.

The analysis of narrative is a primary means for uncovering how disruption is experienced and how continuity is created, and for examining disparities between cultural ideals and people's experiences. Narratives enable the narrator to reestablish a sense of continuity in life. This book is also concerned with the examination of the metaphors that unfold in the discourse on normalcy. The fluidity with which metaphorical images continuously replace one another in an ongoing, culturally informed process quickly becomes apparent when we read people's narratives. Anthropologists explore metaphor not for the metaphors themselves but for the cultural foundations of metaphor.\textsuperscript{54} In this book, metaphor provides insights on the cultural foundations of U.S. society.\textsuperscript{55}

\textbf{STUDIES OF DISRUPTED LIVES}

To illustrate how cultural meanings of continuity frame the experience of disruption to daily life, I draw on five studies of people in various phases of life in the United States. The five studies are about (1) the experience of infertility, (2) midlife disruption and change, (3) life reorganization after a stroke, (4) late-life transitions, and (5) the experience of chronic illness among older members of ethnic minority groups. These five studies are part of two long-term ethnographies I have been engaged in simultaneously, one on the experience of living with a chronic illness, especially in later life, and the other on the experience of infertility and related disruptions in midlife. Both of these ethnographies have been in progress for the past fifteen years and are likely to continue in one form or another for some time to come. Both are based on years of in-depth interviews, which are supported by observations of participants in a variety of settings and under a wide variety of circumstances.\textsuperscript{56}

The five studies described below can be characterized in a word or two, and these characterizations will be used to refer to them throughout the book.
1. *The Infertility Study* (Gender and the Disruption of the Life Course Structure). I began the infertility study after spending several years addressing my own infertility. It was the first time I had chosen a topic I was directly and personally involved with. The study, conducted with Robert Nachtigall, explored, first, how the discovery of infertility disrupts cultural expectations about the structure of life and, second, how men and women differ in their responses to unwanted childlessness.

After conducting a pilot study with 36 couples\(^57\) we carried out a larger study with 134 couples and 9 women without their partners who were either undergoing medical treatment at the time of the first interview or had completed medical treatment during the preceding three years. The majority had undergone medical treatment for three or more years, although 20 persons had undergone medical treatment for a year or less. These women and men were recruited from medical practices, adoption counseling services, low-income clinics, and a self-help group and by others already in the study.\(^58\)

2. *The Midlife Study* (Midlife Disruption and Change). I began the midlife study at the conclusion of the pilot study on infertility because I wanted to understand the meanings associated with other disruptions in midlife. In the end, the infertility study turned out to be not just about infertility. The disruption of infertility triggers women's and men's rethinking not only of all the disruptions they had experienced in their lives but also of other disruptions that occurred during the course of the study, for example, deaths of family members, sudden job loss, and the onset of illness. I wanted to know whether disruption from infertility differed significantly from other kinds of disruptions for people in the same age group. I therefore explored the impact of a variety of disruptive events on the lives of twenty women and men between the ages of thirty-five and sixty-five. This research was shaped to some extent by issues that are common at this time of life. I recognized from studying infertility that disruption can be a catalyst for change. I wanted to understand how men and women interpreted changes, what
provoked them to change, what followed change, and how these changes affected their identity. These men and women were interviewed once or twice in great depth about disruptive events they had experienced, their interpretations of these events, and the impact these events had on their lives.

3. *The Stroke Study* (Sociocultural Mechanisms of Rehabilitation in Old Age; Chronicity and Life Reorganization after a Stroke). The first of three studies of chronic illness in later life, the stroke study, which I conducted with Sharon Kaufman, explored the ways in which elderly persons' lives were altered by the abrupt onset of a chronic, disabling illness, namely, a stroke. This two-part study included (1) patterns of rehabilitation, which focused on acute care, rehabilitation, and the transition to home or institution after a stroke (102 persons over the age of forty-five), and (2) patterns of life course reorganization, which focused specifically on people who returned home after rehabilitation (115 persons over the age of fifty). Our total sample for the two studies was 214 persons, of whom 100 were interviewed three times over the course of a year. In the first study, respondents were recruited while they were inpatients in an acute care hospital; in the second study, they were recruited from the hospital's home care services after discharge from the hospital.

This was the only study in which respondents were not always able to tell a fully elaborated story. The serious medical problems that brought them into the study interfered with their ability to participate in interviews. Their symptoms included weakness and partial paralysis, memory losses, problems in comprehension, organic and reactive depression, uncontrollable emotions, speech impairment, disorientation or confusion, impaired judgment, and chronic fatigue or weakness. Despite the limitations these deficits imposed on their ability to communicate, people who had had a stroke struggled to share their experiences with us.

4. *The Late-Life Transitions Study* (From Independence to Dependence among the Oldest Old). A second component of the ethnography of chronic illness in later life, the late-life transitions study, also
conducted with Sharon Kaufman, explored the transition from independence to dependence following physical impairment of loss of health among persons age eighty and older. After years of research on aging, I continued to have unanswered questions about older people's health transitions. What factors precipitated these transitions? Why did some lives seem to completely unravel, even after a precarious balance had been maintained, sometimes for years? Why did health transitions so often result in lessened independence? Why was there frequently such a wide disparity between elders' views of their impairments and autonomy and health professionals' views of those same impairments?  

This study had two distinct parts. In my portion of the study, forty-four people were interviewed two or more times. They were selected—from health clinics serving older people and from other health-care institutions—because they were undergoing a transition that affected their independence or were viewed as being vulnerable to such a transition. The interviews focused on everyday life, with an emphasis on perceptions of life disruptions, major as well as minor. Most often, the disruptions were linked to decreased physical function. For example, changes in physical function sometimes resulted in forced moves, which precipitated a disruptive transition, although the majority of persons lived at home at the time of the first interview.

5. *The Ethnic Minorities Study* (Cultural Responses to Illness in the Minority Aged). The ongoing ethnic minorities study, with Yewoubdar Beyene, Edwina Newsom, and Denise Rodgers, examines cultural responses to illness of 240 women and men age fifty and older. It draws on several ethnic minority groups (African Americans, Latinos, Filipino Americans, and Cambodian Americans). I include only data from the first twenty-four African Americans because these data had just begun to be collected at the time I was writing this book. The research focuses on the onset or worsening of chronic illness and on people's views of their illness and its effects on their daily lives. We recruit the persons in this study from home care services, from health clinics for low-income people, and
from community contacts. We interview the participants in-depth three times at six-month intervals about their experience of illness, their religious beliefs, their health practices, their identity, their family relationships, and their access to health care. Most have multiple chronic illnesses that interfere with daily life. Incomes vary for the people in this study, but most live at or just above the poverty line. Recent changes in the health-care system, as well as changes in social services and health-care coverage for low-income populations, pose a particular problem for the people in this research, who have few economic resources and many health problems.

The five studies share several methodological commonalities: (1) they are all based primarily on in-depth interviewing, (2) they are all longitudinal with at least six months elapsing between interviews, and (3) the data from all the studies were analyzed qualitatively by means of one basic process.

As different as their ostensible topics are, these studies share a common conceptual focus: the disruption of personal meaning and the consequent destruction of a sense of continuity. Taken together, they encompass an array of age groups, health problems, classes, and ethnicities. Using examples from all the studies makes it possible to consider a range of concerns.

These samples represent different age groups. For example, the age range in the infertility study was twenty-eight to seventy-one with a mean age of thirty-eight, and the age range in the stroke study was forty-eight to one hundred five with a mean age of seventy-two. Not only were the daily concerns of persons in these samples different, but, depending on the nature of the disruption, their lives were informed by historical differences and by social, cultural, and economic changes. For example, most respondents in the stroke study were born before the Great Depression. All had lived through World War II, and some had been born before World War I. Some were refugees from Eastern Europe, while others were the children, grandchildren, or great-grandchildren of slaves or immigrants. Those born in the United States were often from rural areas.
The work ethic and an ethos of “rugged individualism” characterized the values of this sample, which was primarily working class and lower middle class. Most had no formal education beyond some high school.

In contrast, most of those in the infertility study were born after World War II. The economy was robust during their formative years, and the wars fought during that time had different social impacts. These people often came from families with ethnic and class characteristics similar to those in the stroke study, but the majority of respondents in the infertility study were middle class and affluent, predominantly college educated, and employed in white-collar and professional jobs. Although the work ethic, autonomy, goals for the future, and control over the environment were also valued by the people in this group, they were valued differently. Thus there were considerable variations, for example, in ideas about the use of the health-care system, about the role of women, and about the place of work in everyday life.

While people’s responses to disruption varied by age, ethnicity, gender, class, and health, there were similarities in how discontinuities and efforts to create continuity were portrayed metaphorically. These similarities suggest that the narrator’s experiences elicited cultural meanings of a highly specific nature. That the responses have in common the use of similar metaphors to make sense of disruption, limbo, and efforts to create continuity suggests that core constructs in U.S. life persist despite generational change. This multifaceted approach to change and continuity, initiated by respondents and developed in their narratives, suggests that continuity is embedded in the cultural ethos of North American society.

Educational background and socioeconomic status often affected the selection of specific metaphors: for example, upper-middle-class women and men often used science metaphors. However, lower socioeconomic status did not preclude the use of metaphor or the ability to be articulate. Indeed, some of the most articulate narrators in this book have modest educational backgrounds.62

I selected narratives for this book on the basis of several criteria. (See the appendix for more details of the selection process.) First, I tried to select narratives to reflect diversity, to demonstrate a range of experience.
across gender, age, ethnicity, education, and class background. To some extent my ability to do so has been limited by the nature of the studies; for example, four-fifths of the persons in the infertility study were white/non-Latino and middle class, and from the ethnic minorities study I have drawn on data collected with African Americans only. Second, I tried to select cases that reflected frequently mentioned topics such as the process of trying to recover from an illness. For example, people invariably talked about disruption to their lives and feelings of being in limbo. In all cases, I chose narratives in which the general content, if not the particulars, was representative of the data as a whole.

The people whose voices are heard in this book are all struggling to make sense of their lives after a disruption. The disruptions conflict with their assumptions about the world. These people are questioning and trying to make peace with particular cultural ideas. Although culture is an abstraction, it becomes much more concrete when people experience disruption; they may “see” culture as they identify those cultural norms that pose problems for them. As they step outside themselves and try to look dispassionately at the cultural norms that cause them distress, they become anthropologists. They raise questions about what is meaningful. This book may therefore be seen as a collection of people’s dialogues with culture and its constructs through both body and narrative.