

## 'DISCOVERING' CHRONIC ILLNESS: USING GROUNDED THEORY

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**Abstract**—This paper focuses on using the grounded theory method to study social psychological themes which cut across diverse chronic illnesses. The grounded theory method is presented as a method having both phenomenological and positivistic roots, which leads to confusion and misinterpretations of the method. A social constructionist version and application of grounded theory are introduced after brief overviews of the method and of the debates it has engendered are provided. Next, phases in developing concepts and theoretical frameworks through using the grounded theory approach are discussed. These phases include: (1) developing and refining the research and data collection questions, (2) raising terms to concepts, (3) asking more conceptual questions on a generic level and (4) making further discoveries and clarifying concepts through writing and rewriting. Throughout the discussion, examples and illustrations are derived from two recent papers, 'Disclosing Illness' and 'Struggling for a Self: Identity Levels of the Chronically Ill'. Last, the merits of the method for theoretical development are discussed.

### INTRODUCTION

The grounded theory method provides a set of useful research strategies for studying the experience of chronic illness [1-5]. This paper focuses on using the grounded theory method for studying people with a wide range of chronic illnesses to address how *chronicity affects ill people's self-concepts*. Throughout the paper, ways of using grounded theory to develop social constructionist analyses are explored. As used here, the term social constructionist means: (1) Ill people's creation of taken-for-granted interactions, emotions, definitions, ideas, and knowledge about illness and about self and (2) Researchers' sociological constructions which they develop, in turn, by studying chronically ill people's constructions.

Chronically ill people, like most everyone, experience their constructions as reality; their constructions are neither convenient fabrications nor idiosyncratic inventions. Rather, ill people's constructions reflect their understandings of their experiences as well as the diverse situations in which they have them [6]. Further, their friends and family often support their constructions even when these constructions challenge or contradict those of medical professionals, and even when ill people cannot make their constructions credible or negotiable. Grounded theory analyses can then provide physicians with alternative understandings of patients' beliefs and actions than those readily available in clinical settings. Subsequently, physicians may use these understandings to improve communications with patients and to act on problems which patients define.

Like Foucault's [7] argument about the conditions giving rise to discursive practices, this constructionist view acknowledges that outcomes result from social interactions, negotiations and power. However, my application of grounded theory derives from a symbolic interactionist perspective tempered by Marxism and phenomenology. Symbolic interactionism assumes that human action depends upon

the meanings that people ascribe to their situations [8-11]. These meanings derive from shared interactions, which turn on the pivotal role of language. The symbolic interactionist assumption of the indeterminacy of action rests on the human capacity to objectify self and to ascribe meanings to self like any other object. Such a perspective can lead to an overly rationalized view of the individual which a phenomenological perspective helps to correct. Because phenomenology means studying the objects of consciousness, it fosters studying emotions [12, 13]. Both symbolic interactionism and phenomenology lead the researcher to look closely at the research participants' interpretations of their actions and situations. Marxist theory can then provide tools for linking subjective consciousness and choice to larger social structures. Moreover, Marxist theory brings a critical posture to examining the data.

For the type of social constructionist view taken here, the *assumptions* underlying these theoretical perspectives and the *questions* flowing from them are perhaps, more significant for the resulting grounded theory analyses than are specific concepts inherent within each theoretical perspective. Symbolic interactionists assume that as thinking, acting, creative individuals, human beings respond to the actions of others after interpreting these others' intent and action. A symbolic interactionist perspective leads one to look at self and meaning as processes. Phenomenologists assume that subjective reality may take varied forms. This perspective fosters the researcher's study of the multiple dimensions and realities of a person's lived experience. Marxists assume that individual psychology is both shaped and constrained by social structure. Thus, a Marxist perspective fosters asking critical questions about how society impinges upon the individual and how individuals reproduce dominant ideas within society.

In keeping with Berger and Luckman [14], such a constructionist view assumes an emergent reality fundamentally shaped by social interaction. Hence, a constructionist approach offers an open-ended and

flexible means of studying both fluid interactive processes and more stable social structures [15]. Rather than directly applying concepts such as Mead's "I", "me", and "generalized other", or Schutz' "typification" or "multiple realities", these concepts were used to sensitize me to look for themes and issues within the data [16].

Themes were addressed which cut across diverse chronic illnesses such as multiple sclerosis, diabetes, circulatory disease, renal failure, and cancer. These cross-cutting themes initially included self-esteem, continuity and change of self concept, and relationships between time and identity. After gathering and studying more data, my focus also explicitly included emotions and the self, information-control about self and illness, meanings of chronic illness, and ways of living with it.

Different chronic illnesses give rise to variations and complexity in conceptual development of the crosscutting themes. For example, some chronic illnesses resulted in periodic, progressive, or permanent visible disabilities; other disabilities remained invisible. The kinds of situations posed by such differences were studied as well as how ill people thought and felt about them, and what effects visible disability made when studying relations between self, emotions, information, and time.

My social constructionist version of using the grounded theory method to study illness makes use of four different phases in developing concepts and theoretical frameworks: (1) creating and refining the research and data collection questions, (2) raising terms of concepts, (3) asking more conceptual questions on a generic level, and (4) making further discoveries and clarifying concepts through writing and rewriting. In this paper, I shall illustrate each phase and will draw my examples and discussion of substantive work mainly from two recent papers, 'Disclosing Illness' [17], an examination of ill people's constructions about what, when, and how to tell others about their illness, and 'Struggling for a Self: Identity Levels of the Chronically Ill' [18], an analysis of how and why ill people construct identity hierarchies with specific levels. Throughout my analysis below, I stress the *active* stance and approach of the researcher since I see being active as crucial to using the grounded theory method [19].

#### THE DISCOVERY PERSPECTIVE

##### *The grounded theory method*

Before applying the grounded theory method to chronic illness, a brief outline of its defining characteristics will bring it into clearer focus [20-23]. Like other analytic approaches, the grounded theory method itself offers a way of constructing sociological reality; using the method fosters developing analytic and conceptual constructions of the data. In their sociological constructions, grounded theorists aim to create theoretical categories from the data and then analyze relationships between key categories. In short, the researcher constructs theory from the data. By starting with data from the lived experience of the research participants, the researcher can, from the beginning, attend to how they construct their worlds. That lived experience shapes the

researcher's approach to data collection and analysis. In comparison, more traditional logical-deductive approaches explicitly derive hypotheses from pre-existing theories, which fundamentally structure both the data collection and analysis toward verification of refutation of these hypotheses (and therefore, the theories from which they were derived). Grounded theorists affirm, check, and refine their developing ideas, but they do not limit themselves to pre-conceived hypotheses nor do they follow the prescribed canons of traditional random sampling required for statistical verification.

Grounded theory also differs from other qualitative approaches. Most qualitative approaches stress collecting copious amounts of data before delving into the analysis; researchers using such approaches often complete their major analytic work long after they have left the field. In contrast, grounded theorists use their emerging theoretical categories to shape the *data collection* while in the field as well as to structure the analytic processes of coding, memo-making, integrating and writing the developing theory [20-23]. The 'groundedness' of this approach fundamentally results from these researchers' commitment to analyze what they actually observe in the field or in their data. If they find recurrent themes or issues in the data, then they need to follow up on them, which can, and often, does lead grounded theorists in unanticipated directions. For example, while a graduate student, I conducted a study of caring for ill and dying elders in working-class families [24]. An unexpected theme emerged about the role coroner's deputies played in notifying families about the death of their relative. Checking out that theme led me to further comparative research with coroner's deputies in different settings about their strategies for announcing death [25].

Grounded theorists begin with general research questions rather than tightly framed pre-conceived hypotheses. If, perchance, those research questions are irrelevant in the field, then they develop new, suitable ones or find another field. For example, my prior experiences as an occupational therapist and as a researcher in rehabilitation led me to expect to find chronically ill people suffering gradual or rapid decline. However, suffering and decline varied enormously despite routine clinical descriptions of specific illnesses as downhill and physicians' dire predictions for certain patients. Hence, the research questions were revised accordingly to tap ill people's lived experiences and their constructions of them.

Throughout the research and writing processes, grounded theorists follow interests, leads, and hunches that they find or identify in the data. Then they may gather more data, ask more questions, and check their developing categories. Their emergent categories explain and conceptualize (1) the data, (2) common sense understandings of these data, and, likely, (3) other theoretical interpretations. For example, some people seem to 'deny' illness. But when viewed from an ill person's vantagepoint of desiring to realize identity goals and struggling to have a valued self, that person's behavior becomes understandable, rather than standing as evidence of 'denial of illness' [18]. To illustrate, an ill woman continues to work while having a serious episode of

illness. She does so because she wishes to avoid having illness inundate her life and her identity, not because she disavows its presence.

With grounded theory strategies, theoretical development turns on *theoretical sampling* [20–23]. Here, the researcher collects new data to check, fill out, and extend theoretical categories. In contrast to Strauss [23], I conduct theoretical sampling only after I have defined key concepts. Delaying focused theoretical sampling fosters gaining an in-depth understanding of the realities and issues at hand. Hence, theoretical sampling fits into the research and analytic process much later than initial sampling of sites, people, or documents. By the time theoretical sampling is planned, a researcher would have some hunches or even hypotheses which he or she wishes to check. Thus, theoretical sampling shapes further data collection as the researcher pursues developing conceptual ideas rather than amassing general information. For example, my research led to gathering more materials to specify and clarify the conditions under which ill people form identity goals and to delineate conditions when they revise their goals.

When developing formal theory and forming more generic concepts, grounded theorists take their substantive analysis from one area and conduct theoretical sampling in other substantive areas. Then, they develop and refine their original analysis by using constant comparative methods [22]. For example, my concept of an identity hierarchy [18] reflects ill people's rankings of their identity goals after experiencing loss and uncertainty. To develop the concept, identity hierarchy, for a formal theory, one could check the concept first with people who also face issues of unexpected change, loss, and uncertainty. Thus, a grounded theorist could apply the concept to people who with little warning: (1) lose seemingly secure jobs without having ready access to equivalent positions and (2) must immigrate such as certain Central Americans or Southeast Asians. By studying these people, the grounded theorists might discover other contributing conditions which influence the creation of an identity hierarchy. Then data from contrasting sources could be sampled to help develop variation [26]. Moving across substantive areas fosters developing conceptual power, depth, and comprehensiveness.

The strategies of grounded theory can yield rich data, elaborated categories, and dense analyses with applications across substantive fields. These strategies do not yield statistically verified results, which require random sampling of a clearly identified population. However, survey researchers may test reported grounded theories through standard logical-deductive verification procedures.

Grounded theory studies aim for analytic power and conceptual grasp which synthesize, explain, and interpret the data. The rigor of the grounded theory method depends upon developing the range of relevant conceptual categories, saturating (i.e. filling, supporting, and providing repeated evidence for) those categories, and explaining the data. Similar to quantitative studies, or any other research, the quality of grounded theory studies varies according to the methodological thoroughness, the significance of the research questions, and the incisiveness of

the analysis. Generally, much qualitative research depends on implicit methods and thus, relies on the researcher's intuition and talent. In contrast, grounded theory specifies an *explicit* set of analytic guidelines and procedures which can help any qualitative researcher develop more or less fruitful conceptualizations of his or her data.

#### *Debates and dilemmas*

Clearly, grounded theory differs from survey research and from other types of qualitative research such as ethnomethodology. Variations also exist among proponents of the grounded theory method and within the same proponent at different points in time. My social constructionist perspective represents one variation. Glaser and Strauss' [22] early work represents another. They [22] developed grounded theory when formal theory was becoming more arid and distant from the worlds of interacting people, when the primary value of qualitative research lay in sharpening later 'rigorous' quantitative research, and when field research studies generally remained ethnographic or consisted of analytic description. They attempted to demonstrate that the strategies of grounded theory: (1) brought the researcher close to basic processes and issues that people experience; hence, theoretical constructs at once revealed and covered those realities; (2) provided a method for identifying, capturing and rendering *processual* rather than static analyses; (3) fostered developing a rigorous qualitative methodology with its own integrity and intrinsic values distinct from quantitative research; and (4) offered possibilities from moving qualitative research more definitively toward dense, durable, substantive and formal theories [27].

*Misunderstandings and criticisms.* Like all other methods in social research, the grounded theory method has strengths and weaknesses. A number of the criticisms of grounded theory reflect an incomplete understanding of the logic and strategies of the method.

Such partial understanding can lead to applying inappropriate criteria on which to judge the method [28–30]. For example, Bulmer [28, p. 667] states that Glaser and Strauss's [15] "tabula rasa view of inquiry is open to serious doubt." He accuses them of espousing pure induction since they propose reading the literature in the relevant fields *after* having developed a set of categories.

Instead, reading and integrating the literature later in the research process is a strategy to prompt *exploring* various ways of analyzing the data. But it means only *delaying* the literature review, not overlooking it, or failing to use it. Delaying the literature review decreases the likelihood that the researcher will already be locked into preconceived conceptual blinders upon entering the field and in interpreting the data. Once the researcher has developed a fresh set of categories, he or she can compare them with concepts in the literature and can begin to place his or her study appropriately within it. As Glaser [21] stresses, grounded theorists must do their own analytic work; if they 'borrow' concepts from the literature, then they should ensure that these concepts merit a place in their analysis.

Although Glaser and Strauss are not explicit in *The Discovery of Grounded Theory*, they do assume that researchers have had solid training in their fields. Also, they assume that such training provides researchers with perspectives from which to observe and on which to *build* analyses, not merely to apply them. Glaser and Strauss' method fosters both using disciplinary and theoretical perspectives and contributing to their *development* with new ideas, dense analyses, and theory construction. Emerson [29] and Katz [30] reveal another misinterpretation. Emerson [29, p.97] states "while grounded theory glorifies and tries to further generate theory in its own right, it also treats discovery as a stage prior to verification. This rigid divorce between discovery and verification lends support to the critique of fieldwork as insightful but not rigorous." First, Glaser and Strauss [22] portray the contrast between discovery and verification approaches starkly because they see the need for developing new lines of theoretical development in the discipline. Second, qualitative research generally, and grounded theory specifically, derive from different canons than logico-deductive verification models. Qualitative research typically stresses inductive, open-ended, intuitive approaches to data-gathering and analysis, particularly in the early stages of both. Third, precisely what grounded theory provides is a rigorous method for qualitative studies. Hence, grounded theory must be assessed from internal logic of its own method, not by the inappropriate application of external criteria founded in other methods [31].

How researchers actually *use* the method remains a different issue than whether the method itself possesses rigor and logical consistency. Here, Katz and Emerson come close to reifying traditional verification methods as the only scientific method and therefore, as the only legitimate scientific work.

Most criticisms of grounded theory turn on misunderstandings or misuse of the method. However, the major problems with the grounded theory method lie in glossing over its epistemological assumptions and in minimizing its relation to extant sociological theory. The relation between subjectivist and objectivist realities and levels of explanation remains unspecified. And ways in which grounded theorists use their prior theoretical perspectives remain somewhat ambiguous.

*Potential weaknesses in using the method.* Weaknesses in *using* the method may have become equated with weaknesses inherent in the method. Such weaknesses may also be found in most other types of qualitative research and in quantitative research as well. These weaknesses include: premature commitment to a set of analytic categories [29, 30], unnecessary jargon, and a lack of clarity about key terms such as theory, category, and saturation. Premature commitment to categories means that the researcher has not fully explored the issues, events, and meanings within the research problem or setting and has not gained what Lofland call "intimate familiarity" with it [32].

Like other sociological perspectives, the grounded theory method does lend itself to generating unnecessary, esoteric jargon for labeling categories. Instead, researchers can label their categories with simple,

direct, and vivid words. My earlier jargon included "mobilizing the self" [33], and "encapsulated time" [33], which I have since dropped, and in these two more recent pieces, "supernormal social identity" [18] and "cathartic spilling" [17]. Several more vivid terms include "the restored self" [18], "merged identities" [18, 33], "making a comeback" [33] and "the salvaged self" [18].

In addition to the weaknesses in using the method, problems also may arise from lack of clarity about key terms in grounded theory. Then, such questions arise as: "When has a researcher achieved saturation of a category?," or "What stands as a theory?" One researcher's conceptual framework may resemble another researcher's theory [35]. Qualitative 'theorizing' often remains discursive and imbedded in description, which may reduce it to a loosely integrated conceptual framework. In my view, a theory explicates a phenomena, specifies concepts which categorize the relevant phenomena, explains relationships between concepts and provides a framework for making predictions.

*Phenomenological and positivistic emphases in grounded theory.* The grounded theory method of analysis is just that, a method. My social constructionist version of grounded theory has a phenomenological cast [36]. Glaser and Strauss' earlier works [21, 22] have both phenomenological and positivistic emphases and therefore, sometimes may seem confusing and even inconsistent. They claim to be phenomenological, yet a strong positivistic thread runs through their work. On the phenomenological side, Glaser and Strauss have always emphasized going directly to the real world and starting with issues in it. They then went into hospitals and studied expectations of death from detailed first-hand field observations and interviews [37].

On the positivistic side, the early works on the grounded theory method suggest that the method takes on a life of its own, independent of its proponents and independent of the researcher. Glaser and Strauss [22, p. 34] state, "Our approach, allowing substantive concepts and hypotheses to emerge first, on their own, enables the analyst to ascertain which, if any, existing formal theory may help him generate his substantive theories." Similarly, Glaser [21, p. 5] reiterates, "Grounded theory arrives at relevance, because it allows core problems and processes to emerge." Also, Glaser implies that core processes and problems will similarly reveal themselves, rather than be defined by actors and analysts. Hence, Glaser and Strauss lean toward assuming that the theoretical categories derive from the data and that the researcher remains passive [21, 22]. Here, they come close to positing an external reality, unaltered by the observer's presence. Whether they intended to do so or simply had a theoretical lapse in the midst of methodological claims-making is itself open to construction. Clearly, however, Strauss' [23] recent explication of grounded theory now reveals an actively involved researcher who constructs categories and concepts. Yet, as Denzin [38] observes, Strauss' [23] grounded theory approach remains with the empirical science tradition and displays the tension between being simultaneously subjectivist and scientific.

## A SOCIAL CONSTRUCTIONIST GROUNDED THEORY

A social constructionist grounded theory views the process of categorization as dialectical and active, rather than as given in the reality and passively observed by any trained observer. Hence, a social constructionist perspective assumes an active, not neutral, observer whose decisions shape both process and product throughout the research [39]. In short, the research report is also a social construction of the social constructions found and explicated in the data.

The *interaction* between the researcher and the data result in 'discovering', i.e. creating, categories. In short, the 'discovery' process consists of the researcher creating discoveries about the data and constructing the analysis. How the analyst uses the method and *which questions* he or she brings to the data shape the results. Certainly having a store of sociological concepts cues a researcher to look for constructions around status, power, hierarchy, and self-concept [40]. In addition, the researcher's perspective leads to asking certain kinds of questions [41]. In my studies, they include: How do chronically ill people construct definitions of their illness, recovery, self and situation? Who benefits from their definitions? How do their definitions compare with larger cultural themes and social values? What do these people take as real in their situations; of what are they aware; unaware? How do they feel about others, themselves, their plans, hopes and prospects? Under which conditions do ill people have relative autonomy and control? Under which do they not?

From a social constructionist view, the researcher takes those questions a step further. Whether addressing definitions, awareness, feeling, control, or any experience, the social constructionist attempts to find how each develops, changes and gives rise to consequences. For example, which do ill people believe contributes to their having control over their lives? How do they define that control? In which ways do their conceptions of control reflect larger ideologies? How do their constructions of control develop and change over time and over the course of their illness? What consequences emerge from their constructions of control?

Whatever their particular philosophical stance, grounded theorists build in special data-gathering questions, based on their assumptions and substantive interests. For example, given my substantive interests in the social psychology of time and in the sociology of emotions, I often ask questions such as: "What was time like for you during your hospitalization?" "How did you feel about telling your parents about your diagnosis?" "Tell me about what time was like when things were so uncertain."

The researcher's perspective consists of more than philosophical stance, school of thought, and methodological strategies. It also consists of experiences, values, and priorities. Upon reading my data, a colleague interested in the family sees how family interactions affect communications and decisions about illness. One could take that perspective and examine how families construct definitions of illness and decisions about the ill person. Another colleague interested in science sees these ill people's inventive-

ness. One could then look at how ill people invent liveable worlds.

Similarly, having had considerable experience with chronically ill people may foster developing certain lines of analysis, depending on the nature of that experience. For example, Lubkin's [42] nursing text (which does not take a social constructionist view) stresses both patient compliance and professional advocacy. A social constructionist could take those topics and analyze how professionals construct and act upon their definitions of and criteria for patient compliance and professional advocacy.

The researcher's values—in the case of chronic illness, toward aging, disability and death—may shape the research process in taken-for-granted ways. Further, an over-riding interest in one concept such as stigma or, for that matter, in one specific chronic illness, fundamentally shapes the later analysis [43].

Perhaps most crucial is the researcher's school of thought, which provides the conceptual roots for the categories to grow. Following a social constructionist perspective fosters creating categories of the research participants' beliefs and actions. In order to create categories, the researcher already must have a firm grounding in sociological concepts without being wedded to them. This stance implies a delicate balance between possessing a grounding in the discipline and pushing it further. In my work, concepts such as identity, stigma, awareness, and meaning inform both the data collection and the analysis.

When wedded to concepts in their disciplines, researchers may neither see beyond them nor use them in new ways. For example, a medical sociologist who uses stigma as a definitive concept [16] to order and integrate data, rather than as a sensitizing concept [16], may only apply it as given in the literature instead of using it to ask new questions and to form new leads. Sensitizing concepts [16] alert researchers to central issues to tap without committing them to reproducing the initial set of concepts.

Using the grounded theory method, on the one hand, necessitates developing, refining, revising, and transcending concepts within the discipline. Often, a social constructionist stance elicits a fresh look at existing concepts. That alone contributes to revising and refining them. On the other hand, using grounded theory means dealing with the rendering the actual research data (i.e. interviews, documents, case histories, accounts etc.). When social constructionists study their data, they continually raise the questions: "How?"; "Why?"; "Under which conditions?"; "With which consequences?" *How do people construct beliefs? How do they manage their lives? Why do they think, feel, and act the way that they do? Under which conditions do they think, feel, and act that way? What are the consequences of their beliefs, feelings, and actions?* The 'grounded' nature of this research strategy is three-fold: (1) researchers attend closely to the data (which amounts to 'discoveries' for them when they study new topics or arenas), (2) their theoretical analyses build directly on their interpretations of processes within *those* data, and (3) they must ultimately compare their analyses with the extant literature and theory.

In short, the flexibility inherent in field work more generally assumes special importance in grounded

theory. Grounded theorists start with what they see happening sociologically, and then they interpret it. What happens in the setting or to the research participants shapes the collected materials. For example, studying chronic patients' motivations for being productive did not interest me, despite practitioners' urging me to pursue the topic. Yet over and over again, ill people tried to explain their hopes, plans and intentions—in short, motivations. Hence, the data drew me to address this topic.

Again, the researcher's perspective influences whatever he or she sees within the data. Certainly Mead's [9] theory of emergence, analysis of action, and perspective on the development of self and Strauss' [10] explication of identity shaped my perspective. Since my study focused on issues around self-concept and identity, some questions were asked around those topics and respondents volunteered much other information. Their responses indicated that their motivations vitally concerned them. In addition, their motivations were intertwined with their identity goals. Without an initial theoretical interest in identity, one might miss that connection.

These interpretations of the data dovetailed with my theoretical interests in ways which spurred conceptual development. My questions reflected social constructionist concerns and often rapidly built on my developing concepts. This strategy led to shaping data collection around sociological and analytical interests rather than, in this case, gathering quasi-medical information, or making strictly behavioral recordings. From the beginning of the research, the grounded theory approach fosters the researcher staying on an analytic path, albeit he or she may identify a range of possible analytic paths (see Fig. 1).

DEVELOPING AND REFINING RESEARCH AND DATA COLLECTION QUESTIONS

*The research questions*

By asking how, why and under which conditions an existing sociological concept works in this specific field, social constructionists can use existing concepts as sensitizing concepts as Blumer [16] urges. Such sensitizing concepts become translated into general research questions and into more concrete data collection questions. How pointed these questions are depends on the type and level of theoretical development that the researcher has reached.

Generally, grounded theorists start with a set of experiences they wish to explore—in this case, chronic illness and how it affects the self. From the beginning of my doctoral research, I wished to explore links between having chronic illness, experiencing time, and shaping the self. Hence, these research questions initiate the inquiry: How do chronically ill people view living with chronic illness? In which ways does having a serious chronic illness affect an individual's shaping of self? How is the shaping of self related to the individual's experience of time? After completing one study [33] on those topics, another study was initiated later with 70 more interviews of ill people and caregivers and a repertoire of published and unpublished accounts about or by people with chronic illness.

Exploring the thematic questions led me to asking a set of interview questions that tapped people's chronologies of illness and how it impinged upon their lives. The chronologies gave some sense of the range of experiences people had had as well as how they cast them. Given my interests, questions about

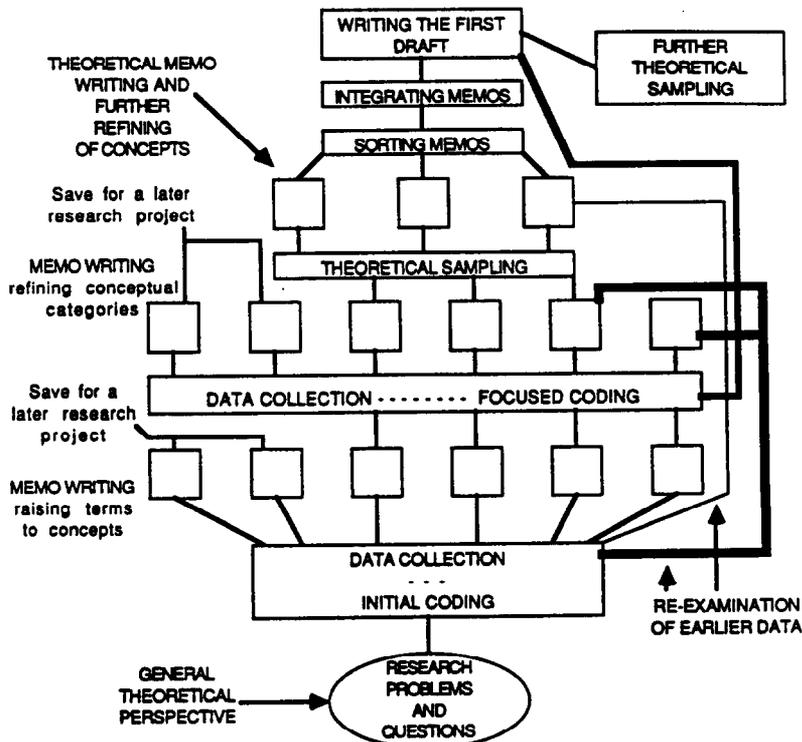


Fig. 1. Research levels in the grounded theory method.

identity and self were built in from the beginning. From those questions and the spontaneous remarks ill people made about themselves, codes and categories were developed describing, synthesizing and explaining the data.

#### *Developing interview questions*

To use the grounded theory method effectively, the researcher needs rich, detailed data. Grounded theorists have been accused of not attending carefully to data collection and of skimming on sampling [32]. However, grounded theorists need detailed, vivid data on which to base their analyses. Unlike some qualitative researchers, grounded theorists may show less concern with ascertaining the 'accuracy' of a specific piece of data than with its theoretical relevance. Two people, such as an ill person and his or her caregiver, may give different account for the ill person's activities. Here, whose rendering of reality comes closer to 'truth' has less importance than the analytic issues raised within each view, as well as the conflicting definitions of each participant. The possibility of someone's account being inaccurate raises interesting theoretical considerations for constructing an identity.

In order to develop a durable, useful grounded theory, however, the data must provide a variety of complete accounts of major issues and processes. By obtaining these data, the grounded theorist can then depict their research participants' worlds. Such data results in developing analyses more easily with more convincing arguments.

Unlike most other types of qualitative data, grounded theorists explicitly shape the materials they gather. Learning to shape the materials well from the start provides the basis for later coding and categorizing. Further, interviewing works well in studies of chronic illness since the researcher often wants to obtain detailed individual chronicles. In addition, participant observation may be impossible for certain types of research problems in this area.

Framing, pacing, and managing the interview questions all affect the type and quality of material the researcher obtains [32, 44, 45]. Since my studies relied heavily on interview data, the incisiveness of the analysis turned on developing suitable questions and knowing when to ask them. Given the nature of chronic illness, several interviews may be needed with a respondent just to get through the basic information about the course of his or her illness, much less tap all the areas the researcher needs to cover.

As Lofland and Lofland [32] put it, the interview should be a "directed conversation". How to direct the conversation depends on the respondent's present psychological and physical status, the relationship between researcher and respondent, the researcher's theoretical perspective, and the topic. Being too directive poses hazards when interviewing chronically ill people. The overly-directive researcher can cut off the most interesting leads and rich data. Further, the researcher may load assumptions into the questions without being aware of doing so [44]. Asking "How did you decide to have the surgery?" assumes that the respondent decided. In contrast, "How did you come to have the surgery?" leaves things open. "Who was most helpful to you during the crisis?" assumes that

others were involved. "Tell me what happened when you had the crisis" allows the researcher to piece events and people together before asking about helpful participants. Both loaded questions above may prove to be useful, when suitable and when raised in logical sequence, i.e. if the researcher senses that the patient played a part in the decision or already knows that other people were involved in the crisis. If not, both questions may raise sticky issues at a time the respondent may not be able to face them.

Briefly, interview questions can be framed and ordered by developing these kinds of questions and leads: (1) short face-sheet, (2) informational, (3) reflective, (4) feeling, and (5) ending. The short face-sheet questions are intended to be neutral, factual and limited to necessary information. These questions set the tone for the interview, so researchers need to be aware of *their* tone and mode of asking them.

The informational questions bring the respondent further into the interview and establish chronology, types of events, degrees of awareness, cast of participants, and the like. If a researcher has established rapport, he or she can bring in reflective and feeling questions. When trust and ease come more slowly, then sequencing them carefully works better.

Given my theoretical interests, the reflective questions may often serve as transitions to address direct issues about self: "How did — affect you?" "How did you see yourself then?" "How would you compare the person you were — years ago with the person you are now?" Similarly, feeling questions also often directly elicit data about self. "Tell me what you were feeling when you learned the diagnosis." "How did you feel about taking the early retirement?" All of these questions help to elicit the narrative of the respondent's story with only minimal framing by the researcher [46]. Ending questions are designed to complete the interview on a positive note [44]. The more intense the interview, the more questions and comments needed to end the interview with the person feeling positive about self. These questions also elicit insights about self. "What have you learned about yourself over the past — years?" "How have you grown as a person after having these experiences?" Such questions elicit interesting data on symbolic meanings of illness and self as well as accomplishing positive closure.

#### *Coding and categorizing the data*

To the extent possible, the codes and categories reflect emerging ideas rather than merely describing topics. For example, I coded some observations of elderly married couples as "merged identities" [18, 33] rather than as family relationships, a more general topic. The codes and categories then help the researcher begin to take the data apart and frame analytic questions about it. In that way, the codes and categories help the researcher to build an *analysis* of the data rather than remain at the level of ethnographic description.

By grounding the categories in the data as specifically yet analytically as possible, the grounded theorist can then sharpen the category, suggest its parameters, begin to outline the *conditions* under which the category develops, and start to look

for consequences of it. Conditions mean those prerequisites which influence and shape views, interactions, and events, rather than determine them. By maintaining this type of analytic posture, even the initial ways of handling the data can enhance developing a theoretical analysis out of it.

A few suggestions for coding. Line by line coding during the initial coding prompts the researcher to study the data, to dispell earlier preconceived assumptions about the data, and to begin viewing the data analytically [20–22]. As a grounded theorist begins to render some codes into categories, he or she defines them analytically and delineates their properties. However implicitly, the researcher's definitions of reality clearly shape what categories he or she constructs. Line by line coding keeps the researcher examining the *collected* data, rather than lapsing entirely into theoretical flights of fancy which have little connection to the data. Yet the researcher can invoke his or her theoretical perspective to raise questions about the data. My theoretical interests, for example, lead to such questions as: (1) Of what larger process is this action a part? (2) How did this action (belief, definition, relationship, pattern or structure) evolve? (3) What do these data state or assume about self and about relationships? By examining the collected data with the theoretical eye, the set of categories developed remains closer to the actual data and simultaneously, moves beyond description.

Coding for processes, actions, assumptions, and consequences rather than for topics leads to greater analytic precision. Coding for processes assists in defining major activities and issues; such coding also helps the researcher to discern connections between structures and events. It helps to look at topics processually. Thus, rather than treating my code, supernormal identity [18] only as a topic, I treated it more processually by looking at the development and abandonment of supernormal identities. Doing so fosters studying the conditions which gave rise to these identities. Similarly, coding for actions fosters the researcher's search for processes. The researcher can then look for phases, contributing conditions and consequences of those actions.

A major strength of the grounded theory method is its open-endedness and flexibility. Since analysis and data collection proceed simultaneously, a researcher can follow up on ideas as he or she creates them. Thus, researchers may use the method to examine an issue thoroughly rather than to rely on previously collected data, which may address the issue incompletely. A grounded theorist may sculpt fully contoured ideas throughout the analysis rather than only suggesting or alluding to them at the end.

The open-endedness of grounded theory allows researchers to pursue leads and ideas as they develop. For example, most of the people who wished to lead conventional lives recounted incidents concerning either disclosing illness to others or avoiding disclosure entirely. Whatever they did, issues around telling people about their illness loomed large to them. Hence, I went back through earlier interviews and sorted material on disclosing and avoiding disclosure. Looking through the interviews with this interest now in mind caused me to find numerous comments and accounts of incidents concerning dis-

closing or avoiding disclosure. (Data coded in one way earlier can be coded several other ways. Similarly, the same anecdote may point to several different conceptual issues.) Subsequently, I built questions about disclosing into later interviews. Doing so helped me to frame a more complete picture of it.

The level of skill of the researcher in collecting data enters here too. As a doctoral student, I knew little about interviewing and initially, felt uncomfortable in doing it. As a result, the quality of the early data differed strikingly with that of the later interviews. In the interim, I had gained both skills and confidence. Since then, I have discovered that many researchers are neither particularly skilled at interviewing nor do they design artful questions. Even practiced interviewers may lapse into 'do you' questions which elicit 'yes' or 'no' answers with limited elaboration.

#### RAISING TERMS TO CONCEPTS

Raising terms to concepts means that the researcher takes a term or code, defines it succinctly, and analyzes it. The wording of the term is important since the researcher now intends to treat it as a *conceptual category*, rather than merely as a *descriptive topic*, or code. In contradistinction to quantitative studies, here a code means a label applied to certain data; a code remains less abstract than a conceptual category. In turn, a conceptual category is part of the researcher's larger theoretical framework in which he or she specifies conditions, offers explanations, and makes predictions. When treating a term as a conceptual category, the researcher specifies its properties, notes the conditions under which it arises, relates how it changes, describes its consequences, and ultimately, specifies its relationship to the other conceptual categories. Descriptive topics, in contrast, may provide vivid accounts but are not integrated into a set of specified and inter-related concepts from which the researcher develops explanations or predictions. For example, I referred to each rung of the identity hierarchy as an identity level [18] and categorized each level. Then, I specified the conditions under which someone moved up or down the identity hierarchy in order to realize a preferred identity. In that way, a set of related conceptual categories were developed and subsequently, the relations between them could be developed.

Two analytic processes contribute to raising terms to concepts—constant comparison and continued questioning. The comparisons include data with data, category with category and concept with concept [20–23]. In my study, comparing data with data means: (1) comparing different people's situations, beliefs, behavior or accounts of the same type of event or issue, (2) comparing data from the same people at different times and (3) comparing properties found in the data with other properties. Comparing different people's accounts means taking some topic such as an experience, issue, period of time, relationship, or stage and juxtaposing data from each person against each other one. For example, comparisons were made of ill people's experiences of discovering and defining illness. Then accounts were compiled to compare the circumstances under which they discovered and defined illness, how they felt, thought and

dealt with it, what they faced at that time, who became involved, and so forth. Just looking at such basic issues systematically yields thick description and often, analytic insights. On a more abstract level, comparing identity goals as illness changed became another unit of comparison [18]. Thus, I learned that some people do plummet down the identity hierarchy as they experience their illnesses. Moreover, a few others start at the bottom of the hierarchy and over months or years move up in it.

Raising a term to a conceptual level means making a series of *decisions* about it. Again, the researcher actively shapes the research process. The researcher creates an explication, organization, and presentation of the data rather than discovering order *within* the data. The discovery process consists of discovering the ideas the *researcher* has about the data after interacting with it. Raising a term to a conceptual level first means deciding that the term reflects a significant process, relationship, event, or issue. Second, it means explicitly deciding to follow up on it in subsequent data collection. Third, it means making connections between it and other conceptual categories.

Again, such terms are not always ones a researcher expects to study. For example, I did not intend to study disclosing illness nor did I have any particular interest in that topic until issues around difficulties in disclosing or avoiding disclosure appeared in many interviews. Ill people attached such significance to these issues, which, in turn, caused me to look at them more systematically and to raise new questions about them.

To raise the term disclosing to a conceptual level, I looked first at my data and then to the literature in medical sociology. I first asked basic questions such as:

- (1) What did disclosing mean to ill people?
- (2) When were they concerned about it?
- (3) What were the consequences of it?
- (4) How did they handle disclosing?
- (5) When did ill people view disclosing as irrelevant?

For many of these people, disclosing meant revealing something private, often potentially discrediting, about themselves. The link between disclosing and ill people's emotions was clear. Later, how these issues intertwined with self-images and self-concept became evident. Therefore, I looked at how people managed disclosing. This meant studying how ill people constructed their actions of disclosing. I raised questions about other ways of telling: were there other types of telling and, if so, how did they compare and contrast with disclosing? My awareness of modes of telling was heightened by an earlier study of coroner's deputies announcing death to survivors [25]. I had long realized that physicians and other practitioners announce, inform, impart, or even reveal bad news. But they seldom disclose for disclosures reveal something about self.

#### *Memo-writing*

Memo-writing provides the pivotal step of breaking the categories into components and elaborating the codes [20–23]. Through memo-writing, the

researcher moves directly into analysis of the data. Bits of data and early codes are systematically examined, explored and elaborated upon. Through memo-writing, the researcher takes his or her emerging ideas apart, checks them, and outlines further data collection. During each stage of memo-writing, the researcher may use his or her theoretical background to deepen the analytic insights of his or her developing grounded theory. My interest in constructions of reality, for example, alerted me to compare people's accounts of disclosing or avoiding disclosure and thereby, to assess the relative amount of reality that they granted to illness.

Basically, memo-writing gives the researcher a tool for engaging in an extended on-going dialog with self [47, 48]. By committing ideas, hunches, questions, and elaborated categories to organized memos, the researcher *defines* what is implicit and what is explicit in the data. In that dialog with self, the researcher looks at the data from a variety of perspectives and analyzes them. Later, the researcher may impose organization upon the memos by ordering them to best capture the data and communicate with the audience. In the meantime, memo-writing gives the researcher an analytic handle on the materials and a means of struggling with discovering and defining hidden or taken-for granted processes and assumptions within the data. For example, my initial respondents' statements led me to sense that the concept of identity encompassed more for them than social location or personal definition. But what was it? As I gathered more data, I realized that they formed identity goals, which took a hierarchical form [18, 33].

The dialog with self through memo-making typically helps to separate the researcher from the researched, thereby reducing problems of immersion in the setting or data, 'going native', assuming the stance of the practitioner and the like. The finished memos form a repository of ideas, which the researcher can then rethink, revise, toss out, organize, and present in varied ways. In a larger sense, memo-writing may never have closure since a researcher may make continued theoretical discoveries as his or her memos become increasingly conceptual. The later memos then may include, incorporate, and transcend extant theory as the researcher develops his or her grounded theory.

#### WRITING AND REWRITING

The discovery process also extends into writing and rewriting drafts for publication. The researcher gains further insights and creates more ideas about the data while writing. Hence, writing and rewriting actually become crucial phases of the analytic process. Through writing and rewriting, a researcher can identify arguments and problems, make assumptions explicit, and sharpen the concepts [48]. Further, the writing process gives the researcher the opportunity to link his or her work with other theories by integrating them into the discussion and analysis.

At this point in the analytic process, the researcher may have a theoretical grasp of the material. But he or she may not have formed the analysis into an argument or presented it as a problem of interest to

colleagues or practitioners for publication. Now, the researcher needs to do a thorough review of the literature in the field. Then he or she can frame the study within that literature and show where and how it fits. The following excerpts show how I located my study on identity and framed the problem [18, p. 287].

People with serious chronic illnesses struggle to have valued lives and selves. Those who live with serious chronic illness experience disrupted plans and altered lives. Their illnesses may cause setbacks, flare-ups, complications, impaired functions and disabilities as well as have social, psychological, and financial consequences. All these experiences and consequences of illness affect whether ill persons lead valued lives and realize their hopes to live on their own terms. Their illnesses pose identity problems that often are left entirely to them and their significant others. How do they handle these identity problems? I answer this question by analyzing the experiences of chronically ill people whose former identities and future plans become questioned, undermined, altered, or negated. By addressing their elusive struggle for a self, my analysis focuses on the consequences of experiencing illness for creating self and identity rather than concentrating primarily on the practical struggles of managing life with chronic illness.

This paragraph sets the stage for studying the problems of struggling for a self and creating valued identities. The category of people who have these problems are specified—those with serious chronic illnesses whose former identities have become questioned. In addition, the focus of the analysis is pinpointed, as contrasted with another major theme in studies of chronic illness—managing to live with it.

In that article, I turn next to the theoretical analysis of identity and introduce the major ideas and arguments. Hence, the reader can discern the framework of the analysis and how the pieces fit together.

Key ideas are as follows [11, pp. 283–285]:

Chronically ill persons' accounts of their experiences reveal two new interconnected issues for studying identity: the role of preferred identities and the development of identity hierarchies. First, individuals choose identities by outlining plans and assessing prospects. The chronically ill people whom I interviewed implicitly developed preferred identities as they attempted to construct lives apart from illness. Their preferred identities symbolize assumptions, hopes, desires and plans for a future now unrealized. In short preferred identities mean identity goals... the concept of identity encompasses the person's vision of future selves, reflecting his or her hopes, aspirations, objectives and goals. In this sense, preferred identities serve as a source of motivation.

Second, an identity hierarchy becomes visible as ill people, over time, choose different types of preferred identities, reflecting relative difficulty in achieving specific aspirations and objectives. The types of preferred identities constitute particular identity levels in the identity hierarchy. These identity levels include: (1) the supernormal social identity, an identity demanding extraordinary achievement in conventional worlds; (2) the restored self, a reconstruction of previous identities before illness; (3) contingent personal identity, a hypothetically possible, though uncertain, identity, because of further illness; and (4) the salvaged self, retaining a past identity based on a valued activity or attribute while becoming physically dependent. Experiencing progressive illness often means reducing identity goals and aiming for a lower level in the identity hierarchy. In short reducing identity goals means aiming for a less preferred identity.

Through writing and rewriting, the researcher can bring out implicit arguments, provide a context for

them, make links to the literature, critically examine the categories and concepts, and present the data cogently [49]. In writing the article cited above, renaming three of my categories enhanced clarity and vividness. Hence, the 'reconstituted self' (it sounded like processed food) became the 'restored self', which captured the idea of returning to a past self and reclaiming former identities. The 'possible personal identity' became the 'contingent personal identity' since the possibility remained contingent upon no further episodes or complications. A 'preferable self-view' became the 'salvaged self' because ill people did more than offer a self-image they preferred; they tried to salvage prior defining traits to claim a valued self now.

Writing and rewriting certainly fosters analytic clarity. These processes also prompt gaining more theoretical comprehensiveness and precision as the researcher grapples with increasingly more abstract theoretical questions and hones his or her responses to them.

#### SUMMARY AND DISCUSSION

Explicating use of a social constructionist version of grounded theory method to study chronic illness reveals issues concerning the method more generally as well as offering some specific guidelines for sociological research in chronic illness. Rather than reflecting a *tabula rasa*, grounded theorists bring to their studies the general perspectives of their disciplines, their own philosophical, theoretical, substantive, and methodological proclivities, their particular research interests, and their biographies. They do not bring, however, a set of finely-honed preconceived concepts and categories to apply automatically. Should grounded theorists apply such concepts and categories—even their own previous ones—to new data, they must justify them.

When using the grounded theory method, researchers actively form questions and seek data. The experiences of people with chronic illness do not entirely unfold before researchers' eyes. Rather, researchers create their analyses. The questions that researchers put to the world, how they collect their data, and which issues and processes they see within it all fundamentally shape their analyses. Further, researchers create a conceptual interpretation of the data, impose an order on it, explicate the relationships between categories, and organize those relationships to communicate their ideas to audiences. Thus, like quantitative researchers [50], grounded theorists make decisions throughout the research process that shape their research products. Also like quantitative researchers, grounded theorists' research reports may take an objectified form and tone that belies the actual research process.

Using the grounded theory method to study chronic illness offers the researcher strategies for focusing and controlling large amounts of data in ways that render it conceptually and, in turn, move the emergent conceptualizations toward more general theoretical statements. Such statements not only deepen sociological understanding of the experience of chronic illness, but also, contribute more generally to the discipline.

The grounded theory method provides the possibility of theory development. The analyses flowing from this approach are ones with conceptual power and durability. But, like other analyses, they can always be refined and modified.

Since grounded theorists believe in studying process, they realize that theories cannot be frozen in time. Certainly changing historical conditions can alter any area of inquiry. Grounded theory analyses can be adapted to changing conditions and can either take historical change into account—or even focus upon it. Grounded theory analyses can also provide future researchers with sources of conceptual, explanatory, and predictive comparison.

From my perspective, grounded theory analyses can be enriched by clarifying the researcher's epistemological premises and by reaching back into extant theory. To date, grounded theorists have not explicated a shared set of epistemological premises. Perhaps there should not be such a set of premises, for researchers from varied backgrounds with diverse research problems can use the strategies of grounded theory. If so, then individual researchers need to examine their own epistemological premises as well as those imbedded in their use of the grounded theory method. Doing so could clarify the relation between the subjective and objective, sharpen the research process, and delineate the theory of reality to which the researcher subscribes. Currently, most grounded theory pieces, including my own, assume a theory of reality. Similarly, some pieces seem to assume the discovery of objectified truth, rather than the discovery of the researcher's more or less useful theoretical categories.

Researching back into extant theory might seem to contradict the entire grounded theory approach. I think not. As noted throughout the above analysis, a strong theoretical perspective can guide questions—from the basic research outline directly into the data gathering and analysis. In that way, a strong theoretical perspective fosters giving the research greater conceptual depth and breadth while firmly situating it within the discipline. More direct ties back to their Meadian heritage could, for example, sharpen grounded theorists' theory of action and assumptions about human nature implicit in their studies. Further, a greater attention to contemporary developments in Marxist and critical theory might foster closer connections between microscopic and macroscopic structures in grounded theory analyses. Such emphases would neither contradict nor negate prior work, but would supplement and extend earlier ground-breaking efforts.

Nonetheless, bringing a strong theoretical perspective to grounded theory studies does pose some knotty problems. Prior theoretical socialization in a researcher may produce ideational and ideological baggage which inhibits forming fresh ideas and promotes tunnel-vision. Yet, theoretical sophistication in classical and contemporary sociological theory can also foster asking fundamental questions throughout the research and analytic processes. Such sophistication leads the researcher beyond training for theoretical sensitivity to create sound analytic questions. Rather, such sophistication leads the researcher to address basic questions of value and meaning. To

discover the conditions which promote this theoretical sophistication instead of theoretical tunnel-vision may, in itself, require grounded theory research.

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