DOCUMENT RESUME

ED 249 678 EC 170 476

AUTHOR	Lincoln, Yvonna S.
TITLE	The Qualitative Construction of Family Histories: The Problem of Multiple Realities and Causality in the Press for Independence.
INSTITUTION	Kansas Univ., Lawrence.
SPONS AGENCY	Bureau of Education for the Handicapped (DHEW/OE), Washington, D.C.
PUB DATE	Apr 84
NOTE	16p.; Paper presented at the Annual Meeting of the American Educational Research Association (68th, New Orleans, LA, April 23-27, 1984). Produced at the Research and Training Center.
PUB TYPE	Speeches/Conference Papers (150) -- Reports - Descriptive (141)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Coping; *Disabilities; *Emotional Adjustment; *Family Attitudes; *Family Relationship; Family Role; Intervention; Mental Retardation; Physical Disabilities; *Research Methodology; Stress Variables

ABSTRACT

A study is described which analyzed 12 families chosen from a five-state area. The families consisted of seven with mental retardation handicapped members, and five with orthopedically handicapped members. Each family was analyzed in terms of family members' contributions to the dependence or independence desired by the handicapped member. Specifically, the study examined the extent to which individual family members and significant others wove stories around the handicap and their roles in coping with it. In depth, repeated, in-home, unstructured interviews and observations of families were carried out. Interviews were taped and transcriptions of the tapes and notes were content analyzed. Three products resulted: a series of case studies illustratng interventions for families at various stress points in the family cycle; a model for family structure, functions, and life cycles to point out changing family structure and the evolution of new roles for family members; and a series of methodological analyses relating to research problems on independence. Examples are cited of the reactions of families to questions of etiology and reality and denial. The idiosyncratic nature of each family's response to the handicap is emphasized, and researchers searching for root causes of family response to handicaps are urged to take a more phenomenologically oriented and naturalistic approach to their studies. (CL)

THE QUALITATIVE CONSTRUCTION OF FAMILY HISTORIES: THE PROBLEM OF MULTIPLE REALITIES AND CAUSALITY IN THE PRESS FOR INDEPENDENCE

Yvonna S. Lincoln
University of Kansas
Center for Public Affairs

Paper prepared for presentation at the Annual Meeting of the American Educational Research Association, New Orleans, Louisiana, April, 1984. This research was performed under a BEH contract to the Research and Training Center, University of Kansas. The opinions expressed in this paper are not necessarily those of the Bureau.

THE QUALITATIVE CONSTRUCTION OF FAMILY HISTORIES: THE PROBLEM OF MULTIPLE REALITIES AND CAUSALITY IN THE PRESS FOR INDEPENDENCE

Introduction and Problem Statement

Sweeping legislation and broad policies have been built to foster independence of handicapped persons. Despite the vast amount of data collected, however, there is neither a commonly accepted definition of independence, nor is there a broadly uniform way of measuring levels of handicapped independence. Independence, like satisfaction and happiness, tends to be a self-ascribed and subjective label. Nevertheless, the creation of Independent Living Centers and other agencies which foster and support the aspirations to independence of handicapped persons depend heavily on this concept.

While disabled individuals can express their desires for independence--often compellingly--it is less often they can tell how they came to want or "need" independence. It is equally disconcerting to researchers that, of two persons with exactly the same type and level of handicap, one may strive for greater independence, and the other appears to rest comfortably within the confines of family dependence. Finally, it is troublesome to both researchers and counselors of families of the handicapped that little research has been conducted on the influence of parents and siblings toward or away from independence.

Objectives

The objectives of the larger study were to: a) explore the contributions of family members to dependence or independence desired by the handicapped member, b) to develop interview and observation-based case studies of families with congenital orthopedic or retardation handicapped members; c) to construct a life-cycle model of stress points to aid in designing family intervention; and d) to examine in depth the presses for independence as constructed by

Figure 1

SAMPLE COPING STRATEGIES AND THEIR EFFECTS

	Coping Strategies	Stresses Reduced	Stresses Increased
-	Denying the handicap and/or problems	Can reduce: Worry about the future Questioning beliefs Guilt and shame	Can increase: Disengagement Poor communication Time demands (on other family members) Increases frustrated expectations
+	Relying on religion/ values	Can reduce: Conflicts Strengthens beliefs Increases sense of worth	Can increase: Guilt/shame
+	Focusing on positive benefits of disabled member	Can reduce: Frustrated expectations Disengagement Negative sibling reactions Comparing disabled member with others	
0	Maintaining routine	Can reduce: Time demands Overt appearance of differences	Can increase: Resistance to life-cycle transitions
0	Creating conventional family appearance	Can reduce: Stigma	Can increase: Resistance to transitions
-	Refusing to plan for the future	Can reduce: Frustration of expectations Time demands Worry about future	Can increase: Sibling concerns Resistance to transitions
+	Reallocation of roles	Can reduce: Role conflicts Marital disharmony Time demands Disengagement of one spouse Inflexibility in life transitions	Can increase: Sibling enmeshment Negative sibling reactions
+	Relying on extended family members	Can reduce: Time demands Limited employment opportunities	Can increase: Role conflicts Disengagement of one spouse

nuclear and extended families. This paper, growing from the objectives of the larger research, focused on the extent to which individual family members and significant others weave stories around the handicap to explain how and why it occurs, and what their roles are in coping with it. What may constitute medical facts sometimes have little to do with the "stories" family members tell themselves or others. These "stories" are forms of coping strategies, in part, of familial myth-making, and reality construction.

When the construction of stories is a form of coping strategy, the strategy can serve to either reduce or increase stress within the family system (or both, as Figure 1 demonstrates). When the construction of stories is a form of familial myth-making it can either help family members to avoid dealing with facts or serve to strengthen the family unit around shared values. In many instances, however, the story-making represents a simple human need: to thread the discontinuity and inherent conflict of experience into a believable, coherent and seamless whole. It is here where traditional canons for inquiry falter and lose their power.

Theoretical Framework

The perspectives for the original case study development were threefold. First, researchers examined the family systems theory of Aponte (1974; 1979), Aponte and Dussen (1981) and others (Fine and Holt, 1983). The main position of these writers is that the family forms a system within which problems are solved, exacerbated, or ignored and whose members make demands upon and contributions to the collective effort. The comprehensive family system model derived from an extensive literature search is depicted in Figure 2. Family members engage each other and are engaged in terms of the family's structure, its functions, its life-cycle and its interaction (the roles which are assigned and accepted).

The second body of literature was that on life-cycles. There is slender research on this area and much of what is known resides in the popular literature, for example, in Sheehy's Passages. Research does suggest, however, that the life-cycles of the family can be divided into eight stages: unattached adulthood, marriage, birth of children, children enter school, children become adolescents, children launched into adulthood, retirement, old age and death. The significance of these stages is that each represents a transition which brings about profound changes in the family structure and accompanying stress. The manner in which the family system attends to, resolves, and makes a given transition (or fails to make the transition) is characteristic of its approach to a wide variety of other problems, including the integration of the handicapped or disablad member.

It is often the case that a family bypasses a transition, or that the family cannot successfully complete movement past a stage. In some instances, the handicapping condition may prevent a young adult from being launched into a single life-style or prevent total self-support. Under those circumstances, the family must cope with reconstructing a set of realities which do not conform to social expectations (a stress-producing activity itself).

The third theoretical framework adopted was that of naturalistic inquiry (Guba and Lincoln, 1983; Lincoln and Guba, 1984, forthcoming). Naturalistic inquiry in an epistemological system (paradigm) comprised of five axioms, all of which stand in direct opposition to the axioms of conventional, or scientific, inquiry. Those axioms include.

1) the nature of reality--reality is multiple, intangible, divergent and holistic (as opposed to single, convergent, tangible and fragmentable, as conceived in the conventional inquiry paradigm);

2) the attribution or explanation of action--there are no "real" causes, but rather attributional shapers; action is interactive, with feedback and feed forward; plausible influences and webs of forces;

3) nature of truth statements--rather than striving for context-free generalizations, the focus is on context-bound working hypotheses, idiographic statements, and differences rather than similarities;

4) inquirier/respondent relationships--conceived as interrelated, rather than independent; and

5) relation of values to inquiry--inquiry is value-bound (Guba and Lincoln, 1983)

These axioms, particularly the first two, suggest, among other things, two important considerations in conducting research: first, that respondent perspectives are co-equal (and occasionally, more important) than researcher perspectives, especially with regard to how respondents may organize and give meaning to their daily experiences; and second, that reality, at least as it has been discussed in traditional scientific circles, is a chimera, impossible to circumscribe or achieve in a research sense. It is, in the best sense of the term, a <u>construction</u> by individuals in light of their beliefs, values and attitudes, the purpose of which is to make sense of the random, chaotic, sometimes tragic and always fluid events and situations which comprise their lives. This perspective on the meaning of reality commends itself to research on family meanings because it recognizes and honors the unique individual and family experiences of living, coping and sharing the life of a disabled or handicapped member.

This perspective is also fraught with uncertainty, as it enables no researcher to say definitively what <u>caused</u> one family to believe--and therefore behave--in this manner, and another, similarly situated, family to believe--and behave--in a quite different mode. What it does do is free researchers from the necessity of looking for a single <u>cause</u> for the family press to independence, and permit them to search out family members' constructions of why their handicapped member has sought--or declined--greater independence. And it permits the representations of those multiple realities as part of the study, each contributing to a holistic interpretation and understanding of why some persons achieve independence and others do not, and how a variety of individuals, handicapped and non-handicapped, from the same environment, define independence differentially.

Methods and Sources

The methods utilized were in-depth, repeated, in-home, unstructured interviews and observations of families (including parents, siblings, grandparents when living or involved with the nuclear family, aunts, uncles and "significant others," such as family priests, doctors and the like). In three instances, when siblings lived beyond driving distance, extensive telephone interviews were conducted in order to enable the research group to have access to all family members.

The sources were a dozen "intact" families (no relevant members unavailable for interview) from a 5-state area, most of them nominated by directors of Independent Living Centers. The families consisted of seven with mental retardation handicapped members, and five with orthopedically handicapped members. The research group traveled to farms, businesses, a legislative office, homes and other places where handicapped persons and their families lived and worked.

Interviews were taped and additional notes were taken as interviews progressed, and transcriptions of the tapes and notes were content analyzed (Holsti, 1967) for data units and larger themes.

The families were identified in most cases using nominations from Independent Living Center Directors and public school personnel, although in two instances, the families were personally known to the investigators and agreed readily to participate. In other instances, the handicapped individuals and/or their parents were contacted; as they agreed to be interviewed, all members of the family system were contacted for their permission to be included via interviews.

Results and Findings

The result of the research included three major products: a) a series of case studies which could be utilized by counselors and policy makers in designing interventions for families at various stress points in the family cycle; b) a model for family structure, functions and life cycle which could be utilized to discuss changing family structure and the evolution of new roles for family members as they moved through cycles in family life; and c) a series of methodological analyses of problems relating to research on independence of the handicapped (of which this is one exemplar).

The first set of problems relates to the traditional assumptions of rigorous research, especially those assumptions regarding causality and reality. Several examples from the case studies themselves are instructive.

On Causality

In one family, for instance, each of four births had been abnormal (premature, extended labor, etc.). But one birth (a boy) had been extremely difficult, and the child was discovered to be moderately retarded. The father of the child was also attending physician (the only physician in an extensive and isolated rural area), although an obstetrician colleague was consulting on the pregnancy Both parents were asked about the etiology of the retardation. The mother responded:

> I have my own personal beliefs about it because an obstetrician, my obstetrician, when I went into labor . . . ordered some kind of very strong sedative be given intramuscularly--which my husband did--and [it] really knocked me out for about two hours . . . then I waked up abruptly with severe pains and then went ahead and had [the baby]. In my own personal thought [it] has always been that possibly whatever medication I was given slowed him . . . and was . . . the reason he was having difficulty, he was sluggish. . . .

But the father commented quite succinctly on the probable cause of the retardation:

> We did not have RNs in nurseries [in those days]. We very kind and sweet ladies who loved babies and took care of them very nicely. . . . and if you had a medical emergency, why, you always call the doctor--it might be ten minutes, might be a half hour by herself, but . . . I happened to be in the nursery at the time [the baby] got into trouble, aspirated and turned blue . . . so I was present about 10 minutes which was enough to get him in the oxygen range that was burning his brain cells out. . . .

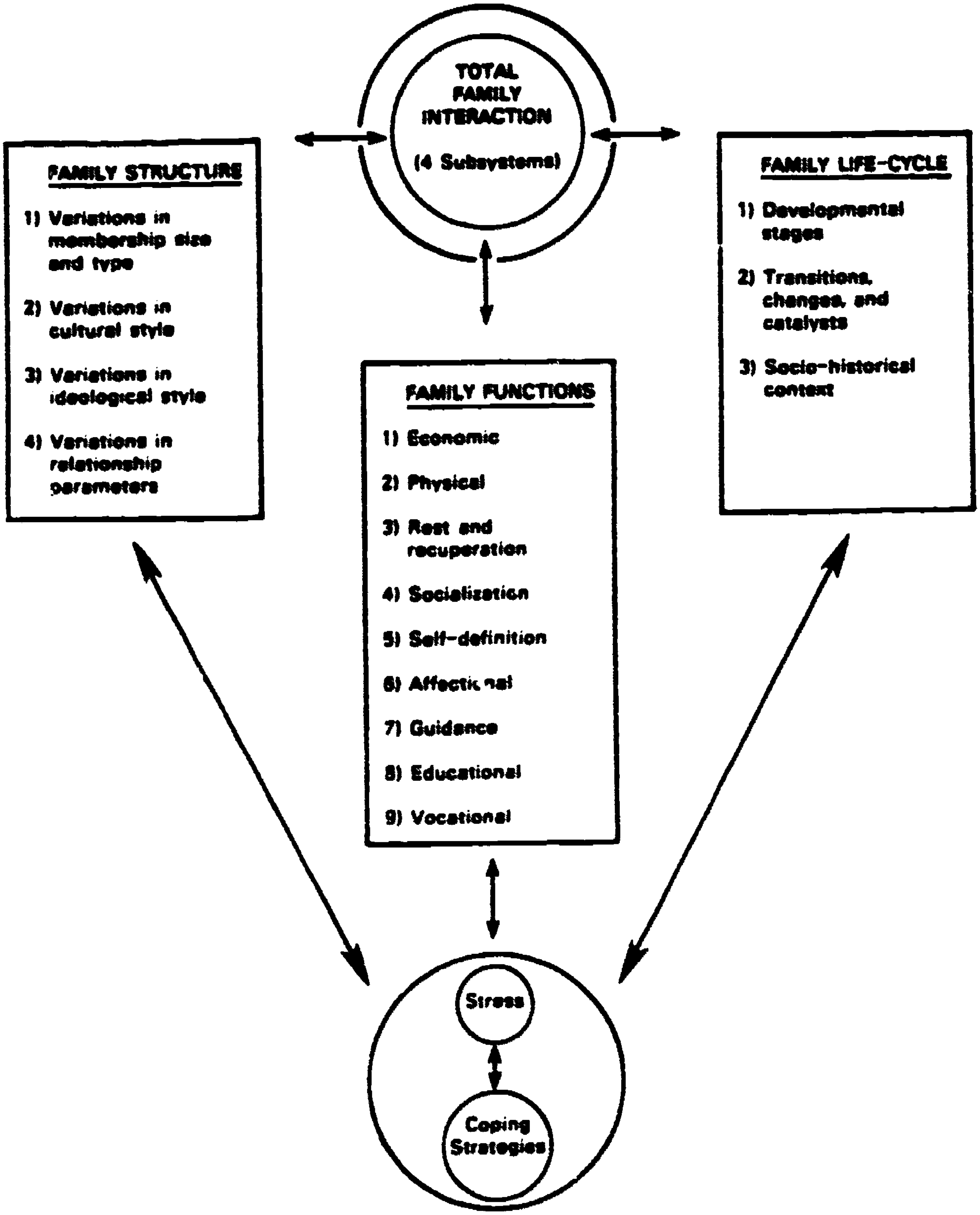
He has a sound medical reason for the retardation of his son: prolonged oxygen deprivation in a premature infant. But she constructs a reason which helps her cope with the guilt typical to parents of retarded children. In fact, the father shares some of the guilt, although he has sound medical reasons on which he can lean:

> There's the guilt factor in there, too. You know that somehow . . . intellectually you'll accept the fact that you're not responsible. Emotionally somewhere back in there you feel that that, well, was there something that I could have done? Was it my position to tell [my wife] when she was highly pregnant you must not clean this dirty house we moved into? Get on off that ladder, we'll just live in the dirt until the baby's here?

The causes for the handicaps, however, are not the only <u>causes</u> families cannot sort out. In a second case, the retarded family member had achieved an astonishing level of independence. He was employed, living alone and self-supporting. Each family member, including the handicapped one, was asked to

Figure 2

FAMILY SYSTEM



what he or she attributed this powerful press for independence. From the handicapped person:

> My father was determined that he would find every he could for me. And he was determined that I should learn not to scratch myself in front of company.

From his father:

> He's independent because all of us--particularly his mother--worked with him constantly from the time he was small and we had faith in God.

From his mother:

> His four sisters worked with him, they created pride him.

From one of his sisters:

> Father is not a talkative man, but he's strong, he's a deep faith in God, and he spent hours teaching [our brother] how to do work.

Where is the truth, the root cause? There are no single causes, only webs of influence woven into the fabric of family dynamics. Each family attributes separate influences to the same observable phenomenon--independent living.

On Reality

The reality assumption--that there is a single, tangible, knowable reality out "there"--is an equally problematic arena in constructing family histories. Representing the family system fairly can only be accomplished by presenting the realities of each of the family members. Those realities grow from the structure and functions of the family and the roles assigned and ascribed within it

It is often the case that family members cannot cope with the stress of the handicap within the family system. They elect to construct realities which help them ignore, minimize or dramatize the situation in such a way as to create other kinds of problems. One example was a family with eight children, the three youngest of whom are handicapped. It is suspected that they have sustained brain damage, although extensive tests and diagnostic procedures have failed to confirm this. The children's early years were characterized by convulsions and seizures lasting occasionally days on end. The symptoms mimicked Tay-Sachs disease although that was ruled out. Each of the three underwent periods of screaming, followed by petit mal and grand mal seizures, followed by periods of hyperkinetic activity. The mother and father are now divorced.

How did the father react to these children? "He ignored it," comments the mother. For years of diagnostic work-ups, behavioral therapy and hospitalization, the mother--who for years did not drive--carried these children on buses to a remote diagnostic center. The children now young adults, are all but one in a special training facility. When the father was contacted for an interview regarding his children's handicap, his response was a classic case of denial:

> I don't know why you'd want to talk with me. I have <u>five</u> children and none of them are handicapped.

His denial of the existence of three of his children is made especially poignant because of the apparent guilt-by-association which he carries: there is a history of epilepsy on his side of the family. This construction of a reality is rather extreme, but it does exemplify the types of coping behaviors which do exist.

Still another family has a teenaged daughter, judged by the research team to be severely handicapped. The young girl is confined to a wheelchair and mentally retarded. Her speech consists of roughly 12-15 words which the family has learned to interpret as her desires for food, drink, or to be moved. The child's ability to perform with even simple learning games, after years of training is virtually non-existent. Yet the parents and older siblings engage in both conversation and behavior which imply this child will "soon be independent." The parents have made no will; the siblings have made no plans for care of their sister; the ILC Director with whom the family has been working counsel she will always be physically, mentally and financially dependent. Still, the family dreams on about the day she will live in an apartment alone, have a job and be self-supporting.

This family's Cinderella dreams for their daughter will be broken as surely as the glass slipper. One can only guess at the event which will ultimately precipitate--and necessitate--their radical reconstruction of the present "reality."

Conclusions

We do know the press for independence is rooted in the family. What we do *not* know is what *causes* this press to be diminished. The construction of family histories from qualitative field work has contributed any number of new findings, but it has not provided *singular*, *linear*, *cause-effect relationships* nor has it allowed for the presentation of a *single*, *convergent family history*. Rather, it has offered webs of influence and patterns of support or non-support, rooted in individual family values. It has also offered not just perspectives, but whole realities of individual family members. The central theme of this particular research might best be characterized as a warning that researchers looking for *root causes* of family response to handicapping conditions will be chasing a holy grail. There are no singular causes in the sense that traditional researchers understand the term. What do exist are a series of realities lived and experienced by various members of these families regarding what it means to be a part of a family with a handicapped member (or to be that person). Those realities speak less to *causes* of the family press for independence (or dependence) than they speak to a series of *constructions* which enable family members to fulfill roles and functions which they inherit or which the family system may assign to them (or fail to fulfill roles which either the family or society may expect them to assume).

Educational Significance of the Study

There are two threads of significance in this study. The first, directed at those involved in special education and service delivery for the handicapped, suggests that the typical mode of designing services without understanding the operation of the family system may be in error. Thinking rather of a series of interventions which respond to stress points with a series of strategies may be more helpful. The second realm of significance is crucial for methodologists, in that it points again to the rigid and unserviceable concepts of reality and causality which have strapped traditional research into handicapping conditions. The assumption of linearly-causal systems and singular realities have confounded and ultimately rendered unusable preliminary studies of families and independence. The search for generalization fails when researchers are confronted with two almost identical situations, each of which produces responses at opposite ends of the behavioral spectrum. The answers thus must lie in complex social and emotional responses which--to be understood--must be embedded in more meaningful and interactive terms than simple "reality" (since there are too many realities for the family members in these cases), or simple "causality" (since there are no simple, linear causes for family members). The shift in philosophy to a more phenomenologically-oriented (and naturalistic) form of research opens studies to the possibilities of unique, situationally-specific responses and the potential for highly-targeted interventions, based on the concepts of holistic family systems and individual family-centered responses to the realities of handicaps.

SELECTED REFERENCES

Aponte, H.J. Organizing treatment around the family's problems and their structural bases. Psychiatric Quarterly, 1974, 48, 8-12.

Aponte, H.J. Diagnosis in family therapy. In C.B. Germain, Ed. Social Work Practice. New York, Columbia University Press, 1979.

Aponte, H.J. and John M. Van Deusen. Structural family therapy. In A.S. Gurman and D.P. Kniskern, Eds. Handbook of Family Therapy. New York: Brunner/Mazel, Inc., 1981.

Fine, M.J. and P. Holt. Intervening with school problems: A family systems perspective. Psychology and the Schools, January, 1983, 20, 59-66.

Guba, E.G. and Lincoln, Y.S. Epistemological and methodological bases for naturalistic inquiry. Educational Communications and Technology Journal Winter, 1983, 14, 233-252.

Holsti, O. Content Analysis for the Social and Behavioral Sciences. Boston: Addison-Wesley, Inc., 1967.

Lincoln, Y.S. and Guba, E.G. Naturalistic Inquiry: Philosophy and Practice. Beverly Hills: Sage Publications, forthcoming.