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WORKSHOP IN HEALTH ADMINISTRATION STUDIES

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"Illness Careers and Network Ties:
A Conceptual Model of Utilization and Compliance"

for

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Rosenwald 405

3:30 - 5:00 p.m.

Selected Sections from

"A NETWORK-EPISODE MODEL
FOR MENTAL HEALTH SERVICES"

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Note: This is intended to provide seminar participants with a broad background of the research underway. The presentation will focus on the further development of the theoretical model which underlies the project.

SPECIFIC AIMS

Traditional models of health care utilization and compliance rely on a static and individualistic conceptualization of how critical health care decisions occur. This proposal recasts these models by hypothesizing that social networks form the mechanism through which individuals recognize mental health problems, contact mental health facilities and comply with medical advice. This reconceptualization employs an "episode" or "illness career" perspective to shift to a dynamic framework. The model lays out critical health care decision stages and specifies how the structure, content and functions of network ties (and how they change over time) interact to influence the course and treatment of severe mental health problems. Some factors in traditional models (e.g., beliefs) are incorporated directly into the model (e.g., as part of the network's content) while other factors (e.g., socio-demographic characteristics) are conceptualized as causally prior, setting limits on the nature of the availability of social network ties. The direct effect of these socio-demographics decreases once network factors have been taken into account. Because work on this type of approach has been hindered by the lack of appropriate instruments, research designs and analytic techniques available to examine dynamic processes and severely mentally ill populations, this study has a critical methodological and statistical component. Standard survey instruments and newly developed statistical tools will be modified and employed to determine the potential utility of the network-episode model developed here.

The basic research questions posed in this study are: 1) To what extent and frequency, and in what combinations, do individuals use friends, relatives, and other network advisors when making decisions about the ways to deal with severe emotional problems? 2) How does the order in which individuals with severe emotional problems seek out those around them inhibit or facilitate contact with professional medical practitioners or facilities? 3) How does the structure, content and functions of network ties influence critical decisions in the process of recognizing problems, choosing professional medical treatment and in complying with medically prescribed treatment regimens? 4) How do traditional explanatory factors such as class background, attitudes, severity and medical treatment regimes shape and modify the influence of networks in compliance and utilization? 5) How do social networks change over the course of an illness episode and how do changes in the structure, content and functions of social networks influence the course of the illness and, in particular, individual compliance? 6) How can traditional statistical techniques be adapted to the study of the process of decision-making for severe emotional problems?

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B. BACKGROUND AND SIGNIFICANCE

The Socio-Behavioral and Health Belief Models are well-known and well-tested approaches in the study of health care utilization and compliance. In Andersen's (1968) Socio-Behavioral Model, three factors form the basis of an individual and rational decision-making process: 1) the accessibility of resources (financial and geographic), 2) the nature of the illness (e.g., severity), and 3) "predisposing" characteristics (i.e., socio-demographics such as gender) known to be consistently associated with utilization (see also Kroeger's 1983 conceptually similar model). In the Health Belief Model, social-psychological characteristics such as attitudes and beliefs are seen as the major determinants of utilization. Both the subjective state of readiness (e.g., beliefs of severity and vulnerability) and the subjective evaluation of circumstances (e.g., perceived benefits, perceived potential barriers) affect individuals' decisions to seek medical care (Rosentock 1966; Becker 1972, 1975; Becker et al 1977). While the former stresses objective measures of "access" and "need", the latter is oriented to a more cognitive framework. Despite this difference in emphasis, these models are complementary, have moved closer together in recent years by broadening their original foci, and share critical assumptions about the nature of decision-making for medical care. Both locate decision-making in the individual. Both see economic rationality as the basis for the decision - individuals weigh the costs and benefits of treatment. Both rely on notions of consistency in individual preferences, perfect knowledge, and on the ability of individuals to make probability calculations undauntingly (Simon 1976: xxvi). Both see decision-making in a static framework conceptualizing it as the act of making a choice from a range of possibilities at one point in time (Fjellman 1976). Both conceptualize group influence only as an additional factor considered by individuals in their rational decision-making calculus (Freidson 1970b: 23ff).

Increasingly, health service researchers have become frustrated with the inability of these models to explain individuals' decisions to seek out medical care when they are ill (Haug and Lavin 1983). And even proponents of the model point to their inapplicability to the salient questions of delay in seeking care, patterns of referral and continuity of or compliance in care (Eraker et al. 1984; Anderson and Newman 1973; McKinlay 1972). Revised versions of these models fail to avoid the central problems outlined here. For example, Eraker et al.'s (1984) Health Decision Model represents, according to its developers, a "third generation" of models inspired by Rosentock's central idea about the influence of motivation on health and illness behavior. The HDM elaborates the social-psychological approach by incorporating ideas about patient preferences and elevates "social interaction" (including social networks) to a single additional explanatory factor. However, the HDM continues to rely on individual motives, is conceptually complex, and has not responded to recent developments in psychiatric theory which focus more on the concept of community (Bass 1978; Svarstad 1986; see depiction of HDM in Appendix I).

Different traditions of research suggest that the assumptions underlying these models are untenable. There is mounting evidence that individuals pass through a sequence of steps to come to terms with a mental or physical illness and that the major mechanism at work in decisions, including but not limited to medical care, is the influence and advice of social network rather than individual rationality (Ailinger 1977; Blackwell 1963; Freidson 1961; Kulka 1979; Weaver 1970; see Pescosolido, 1986, for a detailed review). Previous studies of help-seeking have documented the existence of "pathways to care" (Clausen and Yarrow 1955), "hierarchies of resort" (Romannucci-Ross 1977), "dual use" (Press 1969) and the "lay referral system" (Freidson 1970). Early work on the subject indicated that lay

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"advisors" could facilitate or inhibit individuals use of medical clinics or practitioners (Clausen and Yarrow 1955; Kadushin 1966; McKinlay 1973; Raphael 1969). Friends and family influence definitions of illness and condone or discourage the use of professional care (Freidson 1970a; Levin et al. 1976; Suchman 1964). Outside the realm of modern medicine, faith healers, spiritualists and shamans often function as psychiatrists; other traditional healers continue to be sought out for emotional problems (Fuchs and Bashur 1975; Lee and Glaser 1974; Lubchansky et al 1970; Riscalla 1975; Rogler and Hollingshead 1961). "Counseling" roles are also played by the clergy, police and lawyers who also enter into the process of help-seeking (Cummings and Harrington 1963; Hollingshead and Redlich 1957). More recent studies continue to highlight the importance of a dynamic view of decision-making (Ailinger 1977; Estroff 1981; Horwitz 1977; Lin et al. 1978; Perrucci and Targ 1982; Mosher and Keith 1978). Social networks have been seen as influencing the delay in seeking care for a variety of problems and for following medically prescribed treatments (Callan 1983; Leutz 1976; Froland et al. 1981; Mitchell and Hurly 1981; Mueller 1980; Langlie 1977; Perelberg 1983; Furstenberg and Davis 1984).

In addition to these studies, two other avenues of research provide insights on the deficiencies of traditional models and on the importance of dynamic, social-network based approach. *First*, since Cassell's (1974) classic epidemiological formulation of how "social supports" can buffer environmental stressors, a growing body of research has specified and documented the critical role of social support on adaptation to emotional problems. This avenue of investigation while beset by a conflicting array of definitions, measurement approaches and findings, has provided more than suggestive support for the importance of access to and use of people's social networks during crises which require psycho-social adjustment (see Barerra 1986; Gottlieb 1981a; Lin et al. 1986; Perlin and Aneshensel 1986; Levy 1983; and Thoits 1982, 1983 for comprehensive reviews). The *second* body of research comes from sociologists and anthropologists concerned more generally with the impact of social networks on the values, attitudes and behaviors of individuals (e.g., Mitchell 1973; Burt 1986; Knoke and Kuklinski 1982; Marsden 1987; White et al. 1976). While much of the more sophisticated work over the last decade has concentrated on elaborating the forms of social networks, their influence has been documented across a wide range of phenomena such as employment, migration, family life, community integration and medical care choice, to name only a few (see Alba 1982; Granovetter 1983; Pescosolido 1986 for detailed reviews). These two avenues of research have begun to address one another directly only recently. Social network analysts, according to Wellman (1987) have begun to think about the integrative consequences of network structures (see, for example, Fischer et al. 1977, 1982; Oliver 1986; Marsden 1987; Wellman 1981). Social support theorists, on the other hand have begun to take account of the conceptual distinction between having ties and receiving emotional or instrumental aid from them (Barerra 1981; Berkman 1984).

This brief overview highlights both the contributions and limitations of previous work. While there is a growing consensus about the importance of a dynamic framework, little of this work escapes a static conceptualization or employs a longitudinal research design (Eckenrode and Gore 1981; Salloway and Dillon 1973). Very little of this work addresses the problems of individuals with severe emotional problems or any type of diagnosed psychiatric problem (see Horwitz 1977; Perrucci and Targ 1982 as exceptions). Existing studies on those with severe problems suggest the centrality of network contacts. For example, Estroff (1981) suggests that clients seem to confine their social relationships to others who share similar life problems (e.g., the side effects of drugs). Hogarty et al.

(1979) suggest that schizophrenics withdraw from their social networks to avoid the seemingly "noxious" effects of confusing social interactions. Coates and Wortman (1980) suggest that the severely mentally ill perceive others as uncaring, angry or unavailable for help. But these studies do not document the existence or actual influence of family and friends on care and compliance. In sum, despite the growing consensus that a key to understanding adjustment to psycho-social problems lies in the meaning generated and maintained through on-going social interactions, there is no overall perspective on utilization or compliance based on these insights.

The significance of this study lies in developing a conceptual framework, a "network-episode" model, which can provide mental health researchers with a set of concepts and methods useful in understanding the social dynamics of recognition, treatment and compliance. As such, it will contribute to *basic* knowledge in understanding the networks and processes that shape individuals' health care decisions. Over the past three decades, the focus for treatment of mental illness has shifted from the hospital to the community. Yet we know little about how day to day social interactions in the community affect decisions on treatment, outcome or compliance (Estroff 1981). Understanding the factors that delay visits or encourage non-compliance can inform *policy* makers on the feasibility of corrective programs. Compliance represents a massive problem for psychiatric out-patients: for example, 24 - 63% do not take prescribed medications in correct amounts, at the right times or at all. (Apsler and Rothman 1984; Becker and Maiman 1975; Gillum and Barsky 1974; Krebs 1971; Litt 1985; Siesler 1974; Steffensen and Colker 1982). The inability to transform much of the useful knowledge from previous work lies in the unspecific and global nature of measures used in studies (Hirsch 1986; Gottlieb 1981; DiMatteo and Hay 1981; Wiesenfeld and Weis 1979). The study has a *long-term objective*: it will bear directly on the ability to mount larger studies by developing and evaluating models and methods for studying client groups with severe emotional problems. This exploratory study is small in scale but targets key diagnostic groups. Major depression and schizophrenia represent frequently occurring and severe mental problems. In the United States, recent estimates suggest that there are approximately 700,000 schizophrenics and 700,000 severely depressed individuals. The cost of use of service by these groups, while difficult to estimate, is likely to be high since these groups use several facilities in one year, experience extended periods of treatment and become part of a chronically disabled population (Goldman and Mandersheid 1987).

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C. PRELIMINARY STUDIES

Note: The limits imposed by the reliance of secondary data in my previous work has prevented a full elaboration of a testable network-episode model. This section lays out the assumptions and hypotheses of the model, indicating where relevant, how this builds on previous work, including my own which examines the deficiencies in standard models and explores the utility of alternative conceptualizations.

Since an NIMH study group suggested the notion of pathways to care, the "illness career" or "episode" approach has provided a promising alternative to dominant models of utilization and compliance (Clausen and Yarrow 1955). This view does not require a rejection of factors associated with prominent models of health care utilization and compliance. As Andersen and Newman (1973: 110) claim: "from a theoretical perspective the major determinants of health service utilization have already been defined, such that the need for new explanatory variables is minimal." These other models, in fact, sketch out the major categorical contingencies that influence choice if the perspective is an individualistic, static one. What the network-episode approach does is to shift the focus to the *process* of decision-making, and in so doing, reconceptualize how beliefs, attitudes and knowledge come to influence health care decision, how individuals determine "need" and gather "access" information and explain why other factors posited in traditional models such as education and class, though not directly related, are found to be associated with help-seeking (see Pescosolido 1987a). The focus of this study is on the "Illness Career" -- the onset, course and set of decisions that accompany a *single acute episode*. The career begins, according to Perrucci and Targ (1982) with the first occasion on which an individual displays behavior judged by others (or by the individuals themselves) to be sufficiently different.¹

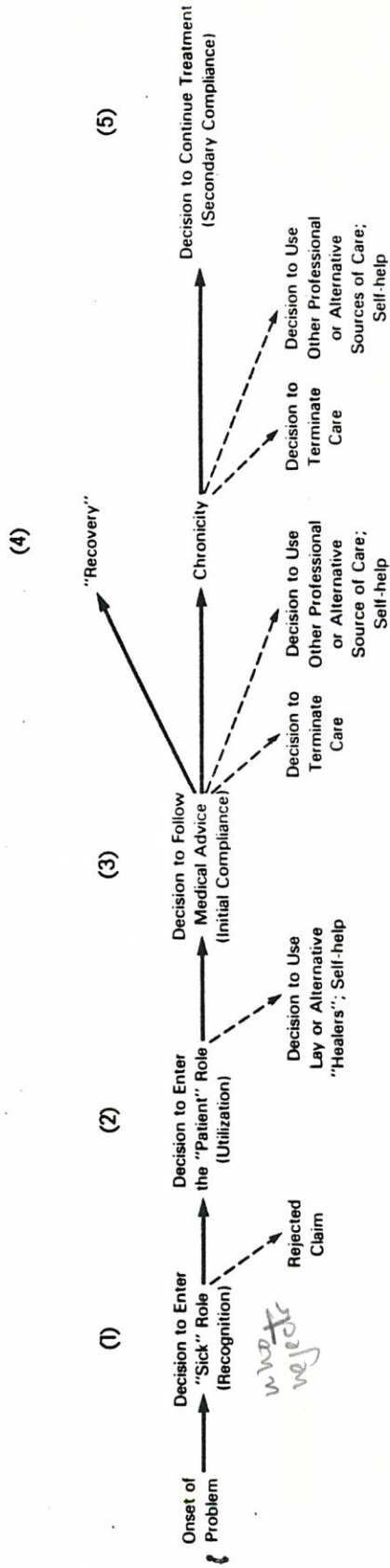
Stages of the onset and course of an illness problem have been set out by Parsons (1951), Suchman (1964) and more recently by Perrucci and Targ (1982). Figure 1 on the following page draws from these models but clearly lays out stages represented by critical decision points through an acute episode applicable to the problems of the severely mentally ill. What this diagram of the illness career makes most clear is that the process of decision-making is a dynamic one. At each of these critical decision points, the individual consults with social network members, if possible, to arrive at the meaning of the problem and appropriate behavior. At any given point of decision-making network, advisors may or may not be called on; these advisors may or may not be the same individuals over time; and may or may not be consistent in their support or advice. According to Hammer (1983), it is possible both that individuals who face severe emotional problems have fewer supportive ties to begin with and that their social networks are decimated throughout the course of the illness (see also Tolsdorf 1976). Figure 1 indicates the two critical decision points under investigation in this study -- utilization and compliance. The term utilization is generally reserved for contact with practitioners of the formal medical care sector (e.g., physicians, clinics). For the purposes of the network-episode approach, the definition

1. Here, the role of the individual (indicated in the parenthetical insert) needs to be added to Perrucci and Targ's (1982) self labelled "radical" view which appears to eliminate the role of individual agency. Of course, in some situations (e.g., severe hallucinations) the individual may not be able to participate in the decision-making. The network-episode model proposed here suggests that individual attitudes, perceptions and coping style can influence and modify network effects.

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Figure 1.

THE ILLNESS CAREER



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employed here is much broader: Help-seeking involves any contact, lay or professional, for advice or treatment during the illness episode. Basically, there are two types of compliance at issue here: taking prescribed medications (drug-taking) and keeping appointments (repeat utilization).² Only a few studies have even mentioned the importance of "peer pressure", values in the client's community or "significant others" (Bissonnette and Seller 1980; Charney 1972; Eraker et al. 1984; Parker et al. 1962; Porter 1969; Stimson 1976; Wilson et al. 1965).

Freidson (1970a: 242) contends that "The concept of an illness career provides a conceptual mechanism that links individuals and their experiences to the community, lay and professional." While ethnographic studies in anthropology (e.g., Janzen 1978; Young 1981) and observational studies in sociology (e.g., Zola 1973) have pursued this avenue of research and have found it to be most fruitful, no overall model has been developed linking process and network. The basic premises of such a model have been laid out in preliminary fashion (Pescosolido 1982) and a revised version can be clearly stated. *First*, all societies hold a vast reserve of people who can be and are consulted during an illness episode. Gurin et al (1960) view society as characterized by a multiplicity of resources that share therapeutic functions. Figure 2 on the following page presents a listing (though not exhaustive) of these (from Pescosolido 1987b). *Second*, a "bounded rationality" rather than economic rationality underlies the process of decision-making. Simon suggests that individuals select from a range of alternatives by "using a simple picture of the situation that takes into account just a few of the factors he regards as relevant and crucial" (1957: xxx). Decisions are made by satisficing rather than maximizing. *Third*, the process of decision-making for individuals is dynamic. Individuals "muddle through" combining a series of decisions over some stretch of time. The patterns and the sequence of advisor choices form "strategies" for help-seeking. Individuals do not have to process all information and arrive at a single choice stamped with indelible finality. Successive limited comparison, in Lindblom's (1959) terms, allows for individual change in response to the consequences of previous choices. *Fourth*, the mechanism underlying the decision-making process is social networks. People make decisions for treatment and acquire attitudes about medical care as they acquire other information — through their network ties. A network tie is defined as any source contacted regarding during an illness episode. These ties can change and produce corresponding changes in individuals' attitudes and behaviors (Freidson 1970; Knoke and Kuklinski 1982; Pescosolido 1986; White et al. 1976). As a result, the networks that surrounds an individual with severe emotional problems becomes a critical resource (Alonzo 1986). It is through mutual exchange (or lack thereof) that an individuals come to attach meaning to their situation (e.g., seeing a problem as amenable to psychiatric treatment).

The basic propositions of the network episode model (both descriptive and probabilistic) can be stated succinctly. Because of space limitations, these hypotheses will be phrased in terms of general concepts rather than each of their specific components. Figure 3 on the following page lays out the specific components, attempting to resolve the tension between the network and social support traditions by conceptualizing a *social support system* made up of a structure of ties, their content and their function.³ In addition, Figure 3

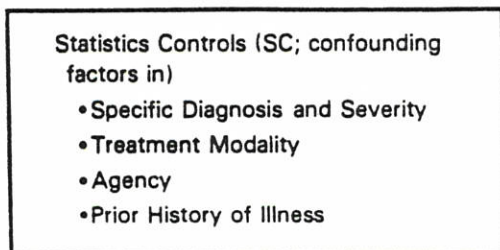
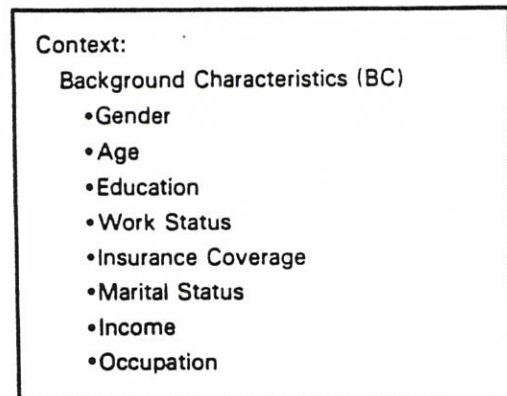
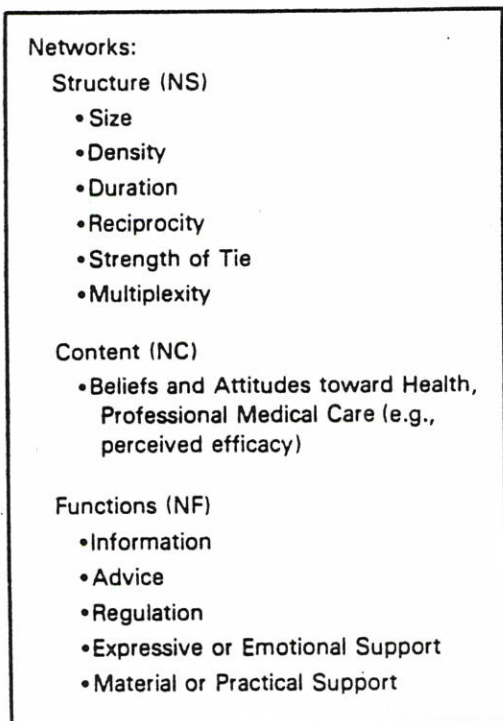
2. Under Parsons' model, such a decision is unnecessary because upon entering the "patient role" the client is obligated to comply and does so.

3. Basically, as the characteristics of network structure change in a direction that allows

Figure 2. Options for Medical Care Advice

A. OPTION	B. ADVISOR	C. EXAMPLES
Modern Medical Practitioners	M.D.s, Osteopaths (general practitioners; specialists) Nurses, Midwives, Opticians, Psychologists, Druggists, Technicians, Aides	Physicians, Psychiatrists Podiatrists, Optometrists, Auxiliaries
Other Medical Practitioners	"Traditional" Healers "Modern" Healers	Faith Healers, Spiritualists, Shamans, Curanderos, Diviners, Herbalists, Acupuncturists, Bonesetters, Granny Midwives Homeopaths, Chiropractors, Naturopaths, Nutritional Consultants, Holistic Practitioners
Non-Medical Professional	Social Workers Legal Agents Clergymen	Police, Lawyers
Other Advisors	Supervisors	Bosses, Teachers
Lay Advisors	Family Neighbors Friends	Spouse, Parents Co-workers, Residents
Other	Self-care	Non-prescription Medicines, Self-examination Procedures, Folk Remedies, Health Foods
None		

FOCAL INDEPENDENT VARIABLES



FOCAL DEPENDENT VARIABLES

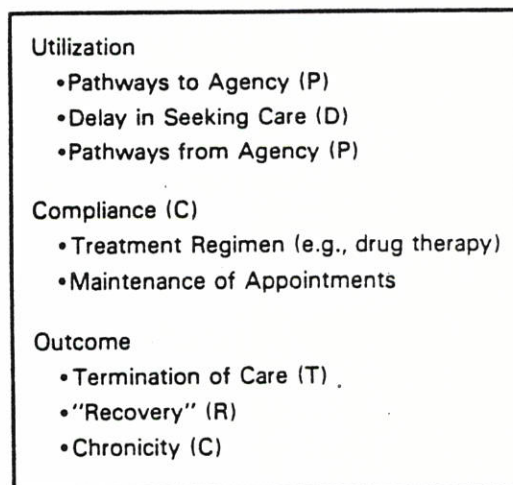


Figure 3. Concepts and Variables in the Network - Episode Model

clarifies that all of the hypotheses listed here are *ceteris paribus* in nature. For example, network effects are expected holding constant insurance coverage, prior history of illness, individuals' coping styles, etc.

Though we know that friends and relatives form a key role in the recognition and disposition of emotional problems, at present, we have little systematic information on the actual patterns and sequences of these consultations for severe emotional problems or whether these pathways are structured by an individual's characteristics. The first set of expectations under the network-episode approach simply involves descriptive hypotheses regarding the networks themselves:

Ia. The search for care is socially organized. That is, a complex but limited set of patterns and sequences of network ties (i.e., seeking both lay and medical advisors) exist. Further, these patterns and sequences are associated, to some degree, with social characteristics such as age, education and gender (Pescosolido 1987b).

Ib. Social networks are in a state of dynamic flux. Severe emotional problems affect the individuals' ability to maintain old ties or generate new ones. More specifically, severe emotional problems result in the overall loss of network contacts over time (Hammer 1983).

The second set of expectations under the network-episode model involve the effect of the structure, content and function of network ties on delay in seeking care and for compliance. Delay is the length of time from onset to contact with a formal medical care advisor. Compliance involves adherence to two basic treatment regimens -- drug-taking and appointment-keeping.

IIa. The structure of networks (e.g., size, density, multiplexity) *interacts* with cultural content to affect delay in seeking care and in complying with drug and appointment regimens.

IIb. The functions of networks (e.g., advice, regulation, emotional aid) *interact* with cultural content to affect delay in seeking care and in complying with with drug and appointment regimens. ⁴

Hypothesis IIa draws directly from Freidson's interactive theoretical model (1970) adapting it to delay and a more rigorous use of network structures (Freidson's original model depicted in Appendix I). As White et al (1976) remind us, networks in and of themselves are not predictive (see also Pescosolido 1986).⁵ Only when considered in the light of socio-cultural context can useful hypotheses be generated. Previous studies of

greater influence (e.g., increased size or density or multiplexity), greater congruence with the orientations of the formal medical care system or more "monitoring", these factors are expected to increase compliance and decrease delays in utilisation as specified by the hypotheses that follow.

4. The possibility of a triple interaction between structure, function and content will also be considered. Wellman (1987) for example suggests that close ties are more likely to provide all types of support while weak ties only provides information (see also Granovetter 1973, 1983; Bernard et al. 1987).

5. In addition, Dean (1986) point out that network structure in and of itself appears to have little causal impact on mental health (see also Lin, Dumin and Woeful 1986).

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network influence on utilization or compliance have relied almost exclusively on whether or not advice was solicited, whether advice came from kin or non-kin, and whether the ties are "strong" or "weak" (Calnan 1983; McKinlay 1973; Kadushin 1966; Furstenberg and Davis 1984; Suchman 1964; see Horwitz 1977; Raphael 1969 as exceptions). However, there appears to be a systematic inconsistency in these findings. Those studies that find network ties facilitating utilization tend to study more educated networks (e.g., Kadushin 1966) while those that find network ties inhibiting the use of medical care facilities study "working class" or "lower class" networks (e.g., Horwitz 1977). This inconsistency can be reconciled by specifying the essential interactive nature of network effects. Clients who have stronger ties will be more likely to behave in ways expected by the network members (DiMatteo and Hay 1981); high density networks, according to Cubitt (1973) are more likely to form norm-reinforcing groups. However this leverage will push individuals to care only if they have what Berkman (1984) calls "pro-care" values (i.e., values congruent with or supportive of formal medical perspectives).⁶ Conversely, it will increase the delay in seeking care if the attitudes, beliefs and opinions among network members conflict with those of the professional medical care system. Clients with few network ties or a sparse network will experience moderate delays even if those ties are "pro-care" because the reinforcement necessary to secure the acceptance of networks ideas is absent. The second hypothesis draws insight from the social support theory. While people must be connected to others to get help, the mere existence of family or other network ties does not guarantee support (Gottlieb 1981b; Wellman 1987). Hypothesis IIb looks at what networks actually do (i.e., their functions) in combination with their overall views on medical care. For example, in "pro-care" networks, if direct advice or information is given or if individuals check on members routinely, delay in help-seeking should be minimal and compliance more likely than if network ties do not provide these functions. As Umberson (1987) suggests, one way that social support may work to produce "healthy" behaviors is through regulation. If emotional support from network members, even close ties, is weak or absent, individuals with severe emotional problems will be less likely to solicit and comply with the values, opinions and attitudes offered in networks (Hirsch 1981). Only by separating out the structure from the functions of networks can there be any clarity offered in understanding how social dynamics of interaction affect decision-making for severe emotional problems.

The third expectation addresses the impact of discrepancies between perceived and actual network structure, content and function:

IIIa. The greater the congruity between clients' perceptions of network configurations and the actual configuration, the more likely that network effects will coincide with expectations under the network-episode model.

This hypothesis draws from Killworth and Bernard's (1976) conclusions that 1) individuals' perception of network contacts do not always coincide with their actual social interactions, and 2) the mismatch between these cognitive and behavioral network data hold theoretical potential for investigation. Studies suggest that emotional distress itself

6. The idea of "pro-care" values is conceptualized here as an ordinal phenomenon with networks having a higher or lower predisposition to formal medical care. Avoiding a dichotomy is particularly useful since network members are unlikely to be completely in agreement on their attitudes, values and beliefs.

hinders the accurate reporting of social support and that perceptions may be more important than actual support (Berkman 1984; Wethington and Kessler 1986). For example, if individuals do not perceive their networks as integrated or as supporting the use of medical care facilities, the ability of the network to exert influence on the client's decisions is reduced. In similar fashion, if an individual only loosely connected to others erroneously interprets the values of networks as "pro-care", the overall network effect may be to reduce delay in seeking care.

The fourth set of expectations address the dynamics of network change on compliance:

IVa. Changes in network structure and function will affect compliance depending on the cultural content of the network.

IVb. Changes in network attitudes toward formal medical care will influence compliance.

If over the course of an illness, the size or density of a "pro-care" network decreases, the probability of patient compliance will be negatively affected. However, for clients whose networks see less value in modern medical care options, decreases in network integration are not likely to increase patient compliance. Here the client is left adrift and compliance would still be predicted at lower levels. Since previous research suggests that clients with severe emotional problems actually choose to retain certain ties and break others, the overall content of the network can also change over time while structure may or may not be affected (Estroff 1981; Tolsdorf 1976). If network size is increased through the development of network contacts associated with the agency, there may be a change consistent with continued compliance. To the extent that lost ties or new ties change the overall cultural content of the networks, compliance behavior will be affected.

The final set of expectations deals with the effect of traditional socio-demographic variables on utilization and compliance:

Va. Socio-demographic characteristics like age, gender will be related to the structure, function and content of networks.

Vb. The direct effects on utilization and compliance will decrease once network factors are taken into account.

These final hypotheses lay out the role of categorical factors. While there is choice in interaction in contemporary society; who one interacts with is not an unencumbered "free" choice (Fischer 1982). Interactions are constrained by factors such as age and education which set limits on opportunities for network formation and interaction (see also Huckfeldt, 1983; Eckenrode and Gore 1981). Suchman (1964) for example, called networks among the those with lower educational achievement "parochial" (versus the "cosmopolitan" ones of the more highly educated) because their orientation opposed modern medical care as an acceptable solution for physical and emotional problems. Wellman's (1987) most recent work begins to clearly lay out how these characteristics are also associated with network functions. For example, women are more likely to give emotional support while material aid is more likely to come from men. Much of the role of social demographic characteristics results from a proxy effect for network structure, function or content.

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There are several advantages to this theoretical approach. First, it shifts to a dynamic perspective without dismissing the insights of previous models of utilization and compliance. Second, it begins to shed light on the conceptual tangle between social support and networks. Third, it develops interactive hypotheses which resolve disparities in findings in the limited literature on networks and utilization which does exist. Fourth, it begins to specify the nature of the influence of social networks on health care decisions.

The model represents the most recent development in the Project Director's long-standing research interest in utilization models and particularly the influence of social networks. Trained as a medical sociologist at Yale University, the P.D. participated in two NIMH-sponsored traineeships: Medical Sociology (Jerome K. Myers and August Hollingshead, Directors) and Psycho-social Epidemiology (Stanislav V. Kasl, Director). Comprehensive examinations were also taken in these areas (passed with Honors). In addition to this training, the P.D. has taught a series of courses relevant to the proposed study. Both at Yale and Indiana Universities, the P.D. taught the Graduate sequence in Statistics for Social Scientists; courses in Methods of Data Analysis and Methods of Social Research; graduate and undergraduate courses in Medical Sociology (Teaching Award 1985). While the P.D. is not primarily a methodologist, research to solve statistical problems important to investigating substantive issues are a concern and demonstrate the ability of the P.D. to address the methodological issues raised in this study. The P.D. has investigated the statistical and methodological problems in the use of official suicide rates (1986b) and the important differences in applying two different statistical techniques in cross-national research. A representative piece is included in Appendix V:

"Confronting sociological theory with data: Regression analysis, Goodman's Log-Linear Models and comparative research" *Sociology* Volume 17 (August: 359-379). 1983.

The P.D.'s substantive research endeavors address health care topics germane to the proposal. The doctoral thesis, *Medicine, Markets and Choice: The Social Organization of Decision-Making and Medical Care*, provided a theoretical guide for analyzing the decision of individuals to seek modern scientific versus traditional indigenous forms of care in over a dozen societies.⁷ The analyses depended on secondary sources of data from a number of archives and individual researchers. The last chapter considers in a preliminary fashion the notion of a "strategy" model in which attention shifts from a single choice to the combination of advisors individuals consult for medical problems. This line of research continues in:

"Migration, medical care and the lay referral system: A network theory of role assimilation", *American Sociological Review*, Volume 81 (August) 1986.

"Reformulating utilization theory: A process-oriented perspective on the Socio-Behavioral and Health Belief Models" (under journal review).

Both are included in Appendix V. In the first, again using secondary data, the role of the social context of professional dominance and the social networks that migrants form are posited as influencing the preferences they hold for medical care during illness. In the

7. Yale, December 1982; Dissertation Award, Medical Section, American Sociological Association, 1983; funded by NCHSR's Dissertation Research Grant Program.

second, archive data from a number of sources are used to examine how the probability of using professional medical care as well as the correlates of these choices are affected by the hypothetical or actual nature of the choice and the individual's previous experience with the problem.

D. DESIGN AND METHODS

Summary. The proposed design is a three-wave panel study over an 18 month period which involves both retrospective and prospective data collection. The repeated measures design allows for the study of intra and inter-individual changes (Nesselrode and Baltes 1976). The study is composed of two target populations: a focal sample of 120 clients with major depression or schizophrenia and a one-stage snowball sample of the core networks of these clients. The focal client sample will be stratified along two criteria: agency and diagnosis. The base for determining the focal sample will be first admissions to a private mental health clinic and a CMHC (i.e., first admissions to *that particular* agency).⁸ This second sample is composed of approximately 480 network members who interact with the focal client participants. While the average number of ties in the general population is quite high (e.g., mean of 12 in Fischer's 1982 community sample), the number for the severely mentally ill is, in practice, much lower (mean of 4; Thoits, personal communication).⁹

Because agency type is confounded with socio-demographic characteristics and networks, the requirement of the two sites is essential and removes the biases of previous studies where networks tended to be homogeneous. As the Time Line in Figure 4 on the next page indicates, a feasibility study will be conducted in Year 1 to modify social support, network and other measures for severely mentally ill populations and to collect background information necessary to mount the three-wave study. This includes ethnographies of the clinic sites, analysis of records (to approximate the number of admissions in selected diagnostic groups during the study), administration of sets of questions (alone and in combination) to determine the ability and tolerance of client groups to provide data. Estroff (1981), working with the chronically mentally ill, found the clients often unable to provide precise or reflective answers. Many of the standard question sets for networks, social support and coping are long batteries of questions (e.g., Dohrenwend et al.'s 1978 PERI life events scale).

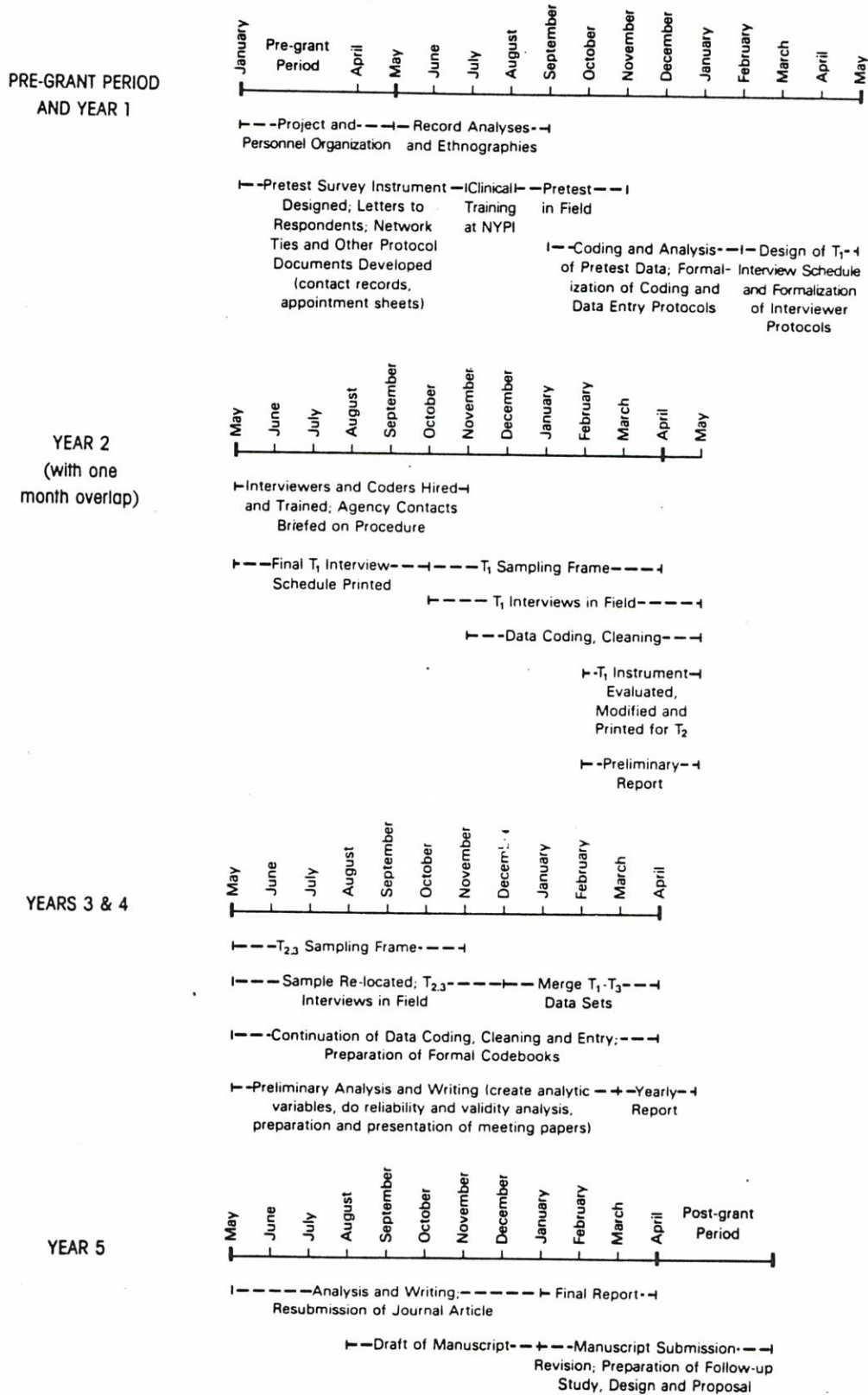
T₁ data collection effort (both on clients and network ties) will focus on pathways to the agency, basic socio-demographic and social-psychological information, and, network structure, function and contact. This study will use a combination of unstructured, semi-structured and structured instruments. The interview will begin with taping the client's story guided by clarifying and directing questions ("thick description", "therapeutic narratives"; see Horwitz 1977; Early 1982; Janzen 1978). This will be followed by the

8. In order to capture the dynamic aspects of the network-episode approach, a long-term prospective design from onset through treatment would be ideal (Calnan 1983). However, given the low rates of incidence of major disorders with the ECA studies (Goldman and Mandersheid 1987) starting in a general population sample large enough to generate a sufficient sample for analysis would be expensive and inefficient. To maximise the theoretical and policy utility of the study, the proposed study focuses on the utilisation and compliance stages of the Illness Career.

9. This represents the largest number of clients possible participants under the budget cap for a FIRST award and is sufficient for an exploratory study of the type proposed here. The study has a sampling specialist who will advise the P.D. at all stages of the data collection; see vita in Appendix II.

Figure 4.

PROPOSED TIME SCHEDULE



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administration of an interview schedule approximately 1 hour in length. The location of the interview (home, hospital or out-patient clinic) will be determined by the treatment regimen. At T_1 , clients will be interviewed as soon as admitted to avoid time and treatment effects (Horwitz 1977). Network ties will be interviewed within the first month after the client's initial contact with the agency. Following Lin et al. (1986), T_1 items will be dropped in subsequent waves if respondents have difficulty answering them, if they do not appear to be valid, if they do not appear to have any impact on utilization or compliance or if they do not change across panels (e.g., gender). In T_2 and T_3 , new items will be added to pick up client satisfaction, compliance and changes in networks. The T_2 data collection will focus on compliance, satisfaction with treatment, and, changes in network structure, function and content (i.e., examining effects of short-term changes on treatment and compliance). T_3 data collection will repeat T_2 measures to examine the effects of medium-run changes on compliance behaviors. The timing of the three waves is not set at equal intervals (see Figure 4). Rather, both clients and network ties will be interviewed upon contact with the clinic (T_1), after 6 months (T_2) and after 18 months (T_3). Previous work suggests that dramatic changes in networks ties after a critical event are likely to occur within 6 months and are likely to stabilize after 12 to 18 months (Pescosolido 1986). Figure 5 provides a schematic representation of the timing of interviews for a potential study participant N. This sequence of waves is designed to capture maximize differences in network changes over time.

Within each agency, a CMHC (the Midtown Mental Health Clinic on Indianapolis) and a private hospital clinic (St. Vincent's Stress Center in Indianapolis) individuals diagnosed with a depressive or schizophrenic diagnosis will be selected as a *potential* study participants (agency contact person will notify the P.D. or Field Director on the day of first contact).¹⁰ However, because of the unreliability of clinical diagnosis, the study Field Director (a clinical psychology graduate student) will be trained at the New York Psychiatric Institute to administer the SKID inventory (see Spitzer and Fleiss 1974; see Budget Justification). Screened clients who fit criteria will be asked to participate in the study. The screening process will continue until 60 clients at each cite (30 of each diagnosis) make-up the target sample. Previous studies suggest that a 25% refusal rate (approximately 18% from clients and 5% from clinicians refusing to let their patients participate) and that a six month time interval would allow for enough time to pick up the target sample size (Horwitz 1977).

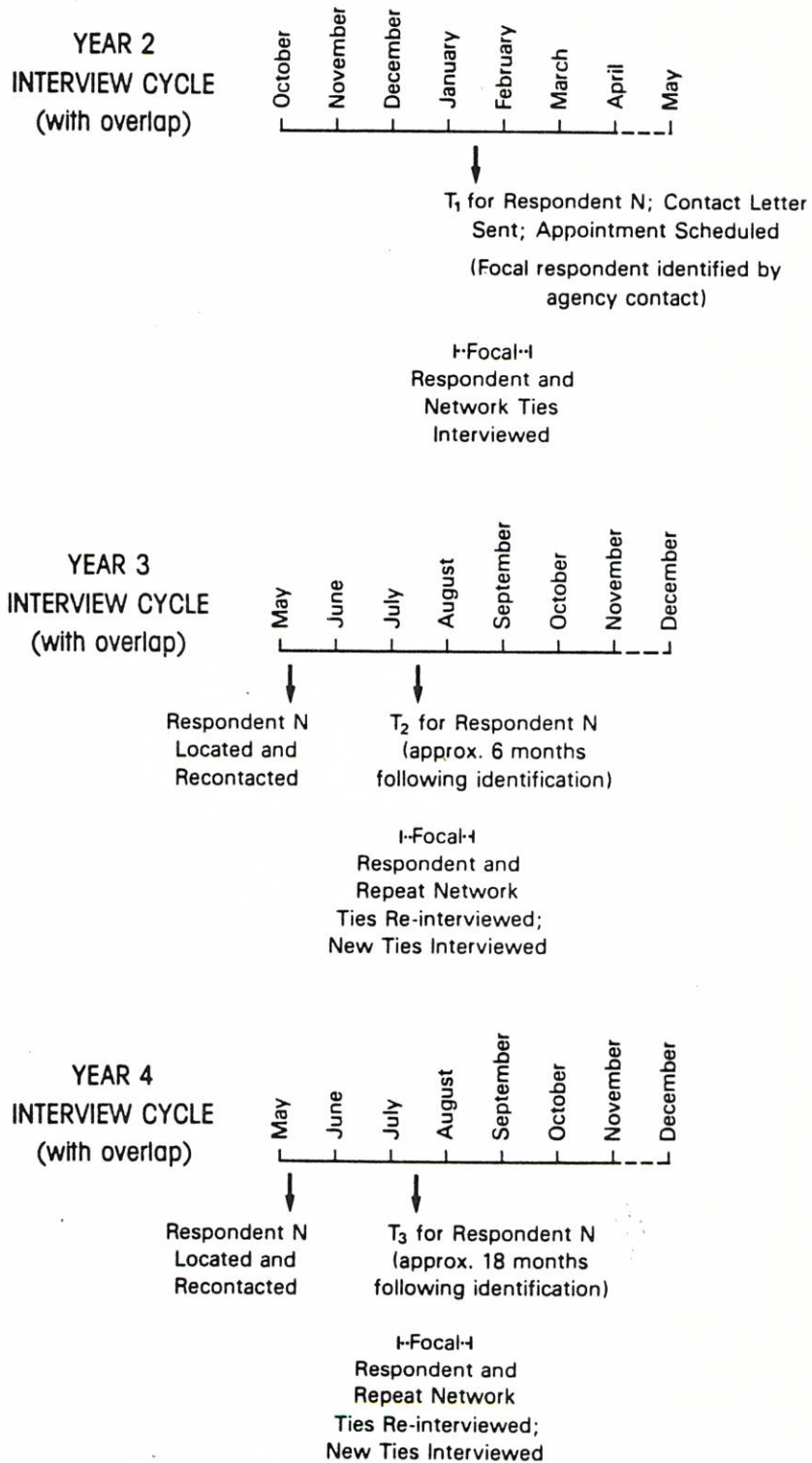
The design has a number of limitations despite its advantages. Although the overall study is longitudinal, episode data at each wave are collected in a retrospective manner which tends to highlight the more dramatic events in the illness episode (Mechanic 1978). This problem can be lessened by designing the recall period in such a way as to minimize error (6-12 months, Shapiro et al. 1984; Lin et al. 1986).¹¹ The sampling strategy has methodological as well as theoretical advantages. First, social support measures are likely to be affected by psychological well-being (Berkman 1984; Gore 1981). Information from the network ties provides useful checks on the reliability of clients' network/support data

10. Verbal agreement to participate has been attained from the Directors of both clinics but formal agreement depends on a Committee review of the proposal. Letters will be sent upon receipt.

11. To see the potential bias resulting from the refusal rate, clients who participate will be compared on socio-demographic characteristics available from the record to those who refuse.

Figure 5.

SAMPLE INTERVIEW STRATEGY (for Respondent N)



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and the advisability of relying solely on such information in similar studies. Second, while attrition rates in panel studies hover around 10% at each wave (Thoits and Hannan 1979), they can be expected to be significantly higher for client populations, particularly schizophrenics. However, network ties can provide location information that will offset this greater panel attrition.

Figure 6 follows and schematically represents the organizational structure of the project. The P.D. will direct the project with the assistance of two individuals, the Field Director and a Data Reduction and Analysis Co-ordinator.¹² To insure the high quality of these data collection efforts, two strategies are employed. First, the P.D., Field Director, her Assistant and Data Analysis Co-ordinator will interview the client sample. The secondary sample of network ties will be interviewed by professional interviewers (see detail in Budget Justification). The P.D. and Research Organization Director have agreed to follow the interview procedures used in the ECA studies (see Eaton et al., 1984 for a succinct summary). Because transcription errors in network data have greater effects on the analysis (Davis 1970; Alba 1982), the professional staff at the Institute for Social Research at Indiana University will handle data entry. This includes typing in the data twice and cross-checking across these duplicate file (see letter from John Kennedy, Director of the ISR in Appendix II).

Measures. As Alba (1982) notes, the collection of network data cannot at present follow firm decision rules or depend on traditional ideas of reliability and validity (see also Killworth and Bernard 1976). Since social support scales routinely include measures tapping the presence of ties, reliability and validity reports on these measures are not useful (Dean 1986; Lin et al 1986). Despite these difficulties, a number of research projects have begun the development of standard protocols for collecting information on network structure, content and function. Given space limits, these will be described in terms of questions sets, described briefly and presented in original form in Appendix III.

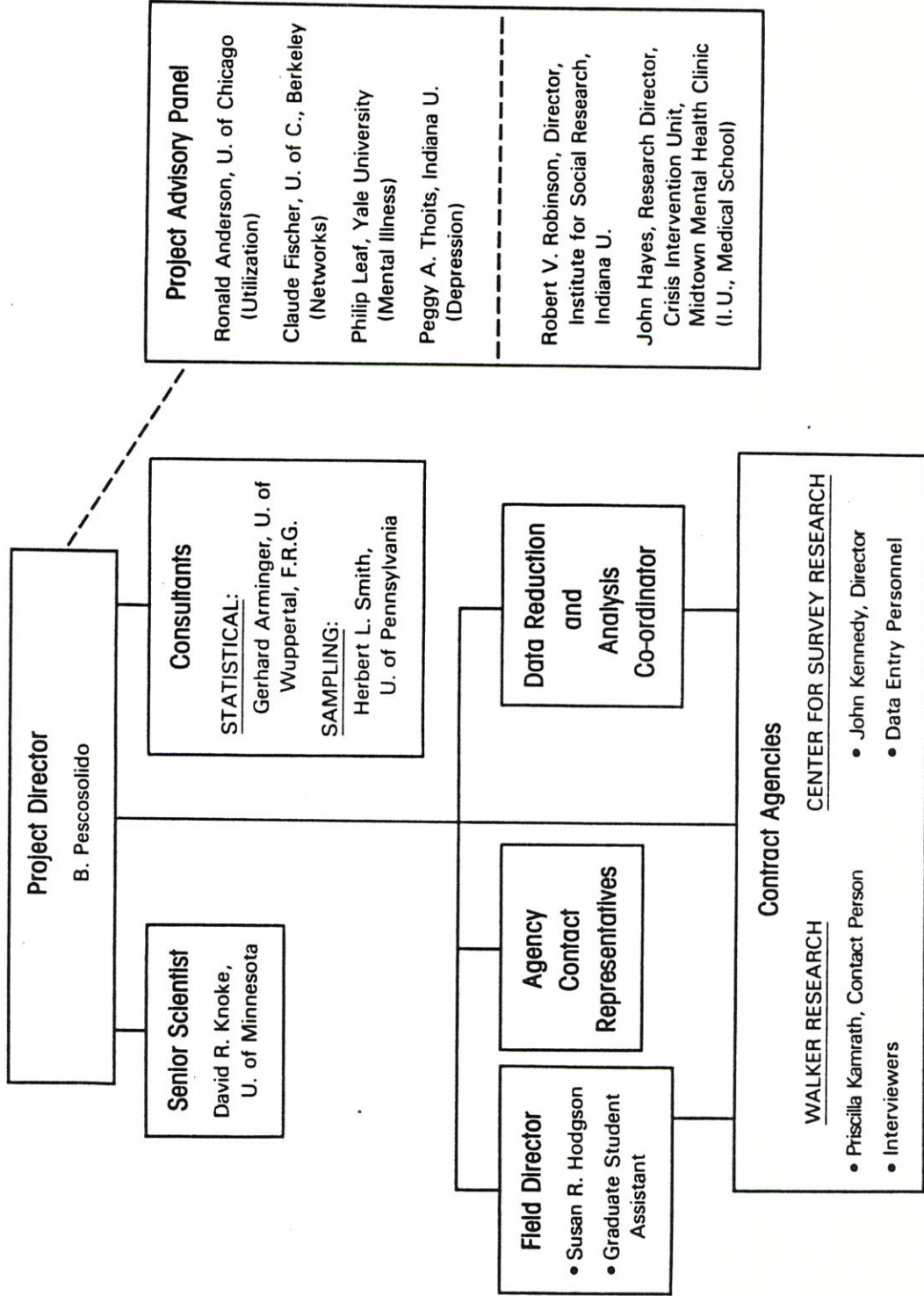
Measurement of network contacts for illness has been approached in two general ways -- "sequenced" questions and "laundry lists". The former, used to a limited degree in the 1976 CHAS studies, include a series of open ended questions that ask respondents to reconstruct their experience during the illness episode. Previous policy-related investigations conducted by the P.D. indicate that the general strategy, with minor adjustments, is promising (Pescosolido et al. 1985; both CHAS and SHAC measures in Appendix). The alternative approach is to ask respondents whether they have or have not consulted any of the types of practitioners or lay consultants on a structured list (e.g., the ECA studies ask a series of "Other Human Services"). This can provide useful accuracy check if placed in a later section of the interview schedule. Information whether or not advice was followed, the perceived severity of the condition at each stage, recovery status or outcome and time intervals between contacts is also required.¹³

12. In addition to the project staff, there is another important organizational component. The Project Advisory Panel is made up of well known scholars who have agreed to lend their expertise to the development of the project (area indicated in parentheses in Figure 6). Clinic Directors and community representatives will be added to the Panel upon formal notification of access to cite and of award. Greater detail on exact responsibilities of different staff members is presented in Budget Justification.

13. In addition to the questions listed above, there will also be a set of questions asking

Figure 6.

PROJECT ORGANIZATION



Utilization studies have rarely proceeded past this point. In the network-episode approach, this information is used to produce a list of network contacts directly relevant to illness (and, in that sense, the "core" network used for the one-stage snowball sample). For each of these contacts, information on density (degree of overlap or mutual contact across ego's ties; GSS Q130; Q 98), size (number of contacts; computed variable), strength (importance of contact to ego; see SHAC schedule), frequency of interaction (how often in contact; GSS Q134), duration of tie (GSS Q135) and homophily (similarity of age, education, religion, race and gender; GSS Q131,132, 136-138) can be obtained for the client (i.e., ego) and also asked of the network ties (providing a reliability check on client data). The General Social Survey (relevant questions in parentheses above) items in their original (for client) and modified (for ties) provide a useful starting point for instrument construction this study (Burt 1986a, 1986b, 1984; Marsden 1987; an alternative version in SHAC schedule).

As Hammer (1983) points out, core networks represent only part of a potential set of network contacts for health care decision-making. The strategy above is unlikely to capture all ties, conflictual or negative ones or those "weak" ties that provide critical information (Wellman 1987; Granovetter 1973). Killworth and Bernard's (1976) results suggest that 16 ties need to be solicited in order to capture 90% of respondents' communication networks. To avoid these biases, Wellman (1987) has developed an elaborate scheme to inventory all network ties including negative ones (see Q II 1., III 1., IX 1., XI 1., in the Wellman schedule in Appendix).¹⁴ Satisfaction with ties, and changes in ties over time will also come from the Wellman schedule (see Q. XIV 7-10; alternative versions available in Fischer, 1982, not shown). Network function questions ask respondents whether each of their network ties provided 15 different types of support (see "East Yorker Aid Questionnaire" and coding sheets in Appendix III). To tap the content of social networks, the WHO ICS-MCU scales which tap "pro-care" attitudes toward medicine in general and physicians and a "tendency to use" measure will be included (see Kohn and White 1976; Bice and Kalimo 1971 on validity and reliability). Others more directly tapping psychiatric treatment are currently being sought. Standard background questions, tailored to the target population including age, gender, religion, education, employment, occupational status and family income will be asked using standard formats from the GSS (see Appendix). Perrucci and Targ (1981) note that the death of a key network member might critically change the ability of a network to deal with a troubled member. Whether or not the individual has a coping strategy disposing the individual to heeding the network's advice matters (see Dean 1986; DiMatteo and Hay 1981; Lin et al. 1986; Tausig 1986). A shortened version of the PERI life events scale will be used to determine "load" on the network and the Pearlin and Lieberman Mastery scale (1979) will be used to measure coping style. Finally a set of checks on interviewer perception of client accuracy and co-operation such as those included by Fischer (1982) or in the GSS (1987) will be modified for use.

Appointment keeping will be determined by checking the client records just before T₂ data collection phase (again, when compared with client recall data, an indicator of reliability results). Drug compliance will be measured in a variety of ways: 1) comparing

respondents to recall other emotional problems prior to the current episode. While not directly relevant to the theory, without this information the data could not be examined with event history models (see below).

14. To the extent that clients' repeat the names of those mentioned, background information on the nature of the ties and social characteristics will not be repeated.

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the instructions on client records with client reports for type, amount, timing of dosages (with clients, color pictures of the most commonly prescribed drugs will be used).¹⁵ 2) asking Apsler and Rothman's (1984) compliance question and Litt's (1985) four-point self-assessment scale (both included in Appendix III). This combination of methods avoids many of the methodological pitfalls of compliance measurement — missing dropouts, compliance bias (i.e., difference between perceived compliance and actual compliance with physicians' orders; Bissonette and Seller 1986; Basch et al. 1983). While self-reports tend to over-estimate compliance, other more costly and time-consuming approaches do not appear to have greater reliability or validity (e.g., physician assessment, tablet counts, chemical drug markers, drug urine tests; Caron and Roth 1970; Litt 1985; Eraker et al. 1984). Measures developed by Eraker et al. (1984) on client agreement with diagnosis, perception of diagnosis severity, fear of side effects and perceptions of regimen complexity will be included (instrument has been requested by the P.D.).

Methods of Analysis: Examining Patterns and Sequences (Hypotheses Ia and Ib). Note: These models are in different stages of development. They are described briefly here due to space limitations and greater technical detail in Appendix IV. Finally, all equations reported below are *estimating equations* rather than formal models where error terms would be specified.¹⁶

The most well-known algorithms developed by sociologists (see White, Boorman and Breiger, 1976; Morrissey, 1982) cannot simply be applied to the data. The basic approach can be altered with methodological innovations to provide a potentially useful tool. Clustering algorithms will be used to see the different combinations of medical care advisors that individuals use when they experience emotional problems. This is accomplished in two steps. In the first, the patterns of use are established; in the second, multivariate techniques (polytomous logits in this case) are used to identify the characteristics of those likely to use particular patterns. Figure 7 on the following page presents a hypothetical density matrix. A high percentage or density indicates high usage of that medical care advisor. By simultaneously looking across the row densities in each block, the types of medical care choices falling together into patterns are identified. So, for example, these results indicate that there are 6 general patterns (that is, after attaching "clinic" as a separate pattern). The high density in the doctor and family columns in the first cluster or block of the matrix means that people who choose doctors are also likely to have consulted their families. Once the patterns are established, the next step requires an appropriate method to determine the social correlates of these patterns. The analytic technique must be multivariate but it must also be able to handle a dependent variable that is measured nominally (i.e., in non-ordered categories). This throws out the possibility of using standard multiple regression techniques most commonly employed in health service research analyses. Multinomial or polytomous logit models are most appropriate in this case.

15. This procedure has been found to increase the validity of drug compliance data (Parry et al. 1971). Information on which drugs are "commonly" prescribed will come from ethnographic and record analyses of the feasibility study.

16. At each wave, where applicable, reliability and validity analyses will be done (e.g., using Chronbach's alpha, Heise and Borhnstedt's rho). Analyses to determine the sensitivity of estimates (e.g., to check for effects of multicollinearity) will also be done.

Figure 7. Hypothetical Results of Clustering Analysis

Pattern	Doctor	Home-town Doctor	Other Doctor	Nurse, Physician's Assistant	Chiropractor	Other "Healer"	Druggist	Advisor, Professor	Resident Assistant, House Mother	Clergy	Acquaintance	Family	Friends	Over-the-Counter Medications	Nothing
Pattern 1	80	0	0	0	0	0	0	0	0	0	0	86	0	0	0
Pattern 2	0	0	0	0	0	0	0	0	0	0	0	0	0	88	0
Pattern 3	0	0	0	0	0	0	0	0	0	0	0	83	68	82	0
Pattern 4	0	82	0	0	0	0	0	0	0	0	0	83	0	0	0
Pattern 5	23	0	0	0	33	32	68	0	0	0	38	88	68	0	0
Pattern 6	0	0	0	0	0	0	0	0	0	0	0	0	0	0	100

By combining the blockmodeling procedures with the multinomial logit techniques, the patterns and their relationship to socio-demographic characteristics can be identified in a direct, albeit complicated manner. The strength of this approach is that it takes as the focus for analysis the set of choices made rather than seeing a single choice as the focus for analysis. However, it does not directly take into account the sequencing (although it can in a crude fashion) of choice nor the timing of the choices.

A second possible avenue to analyze sequences in the illness career comes from the "event history" approach recently developed in sociology (Tuma et al., 1979; Allison, 1984). This technique involves the use of multivariate, discrete state, continuous-time stochastic models to analyze the dynamics of health care utilization. The unit of the analysis is an individual's shift to various medical care advisors which can occur with some probability in any point in time. In this case, then, the basic dependent variable is the unit of time between consulting medical care advisors. The focus is the probability that a certain choice is made allowing a consideration of the sequenced choices and how factors like network structure influence these changes. With the variable forms specified below these models are potentially useful in testing network effects as well. The strength of this approach is that it directly addresses notions of sequence and choice; its disadvantage lies in the very rigorous requirements on the respondent to recall the actual amount of time between choices as well as the advisors consulted. In addition, this technique requires an accounting of illness states that occur before the actual time frame of the data collection.

A third possible strategy to examine sequences avoids the stringent requirements of the event history model. A sequential multi-nomial logit model assumes that there are fixed and equal lengths of time where the transition between states can happen. As such, it has a cost in terms of the actual match with the theoretical processes; however, it may be more realistic in terms of the data collection validity. The development of this statistical model is at an early stage; preliminary work has begun with the assistance of Professor Gerhard Arminger, a specialist in these models. Professor Arminger will serve as a consultant on the project (vitae and letter of agreement in Appendix II).

Testing Network Effects. The most simple and standard way to examine the importance of networks is to consider network variables in standard OLS and logit techniques (choice dependent on level of measurement in dependent variable). The basic estimating equation for *delay in help-seeking* is presented below. The model for compliance (e.g., degree from low compliance to high) would be equivalent in form but predictions of sign would be reversed.

$$(1) \text{ Delay}_{(i)} = a_0 + b_1 \text{ Network Structure} * \text{Content}_{i} + b_2 \text{ Network Function}_{i} \\ * \text{Content}_{i} + b_3 (\text{Social Controls}_{i}) + b_4 (\text{Socio-demographics}_{i})$$

According to Hypotheses Ia and Ib, b_1 and b_2 should be significant and negative in sign. A series of equations needs to be run substituting various indicators of structure and function, and under consideration, a computed measure that attempts to capture overall structure and functions. Not all measures can be introduced simultaneously because of a necessary judicious balance of sample size and degree of freedom used. The set of social controls will be included in all analyses with the following expected effects: PERI (+), mastery (-), prior history (-), availability (-) for example. Additional controls will be added for compliance - for example, perception of diagnosis severity (+), disagreement with medical

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diagnosis (-).

Hypothesis IIIa requires the computation and inclusion of a set of discrepancy measures between individual perceptions of network structure, function and content and actual configurations. For example, in the case below, if the difference is negative, the client perceives network value of formal medical care less than it actually is. In this case, 1) the linear effect of b_5 should be positive (i.e., increasing delay), 2) the size and magnitude of b_1 and b_2 should decrease once discrepancy measures are included, 3) a triple interaction between network structure, content and discrepancy should be negative.

$$(2) + b_5 (\Delta \text{ Client Perception Network Content}_i - \text{Actual Network Content}_i)$$

For Hypotheses IVa and IVb, a change score will be computed from comparing T_1 data to T_2 and T_3 data and the set of variables are added to the basic equation (1). For example in this case, signs should be negative for compliance (e.g., the greater the change in network size, the lower the compliance expected). Similar sets will be computed and included for content and structure.¹⁷

$$(3) + b_5 (\Delta \text{ Network Structure}_{i2} - \text{Network Structure}_{i1})$$

To test Hypothesis Vb, the basic equation (1) will be estimated with the set of socio-demographics alone and then with the full variable set. The expected effects, for example - gender (female -), education (-), income (-) - should decrease in sign and significance. To examine Hypothesis V, a set of equations will be estimated for network structure, function and content. The expectation is that the overall significance will be moderate and effects will be in line with those seen by Wellman (1987). For example, the estimating equation for Structure is illustrated:

$$(4) \text{ Network Structure}_{(i)} = a_0 + b_1 \text{ Sociodemographics}_i$$

17. Two additional strategies will be used to take advantage of waves of data collected over the 18 month period. The first is a very straightforward one: each of the equations described above will be run for each panel. The results will be compared by examining, where appropriate, any patterns in the sign, magnitude and significance of coefficients and the nature of the patterns of choices in the density models. Second, the simultaneous analysis of the information collected over the panel waves can take advantage of the fact that T_1 is not arbitrary but represents a similar and real cohort defining event for respondents. MANOVA (multivariate analysis of variance) allows the examination of why different clients change or don't change in their utilization patterns, or network contacts over time. It also allows a comparison of different groups regarding the nature of these changes. In addition to requiring a meaningful panel entry date, MANOVA requires the same measurement for each subject or equivalent time intervals between panels for all individuals. It does not require that the time intervals between waves be equivalent (see Campbell et al., 1986b; Kessler and Greenberg, 1981).

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F. HUMAN SUBJECTS

As noted on the attached form HHS 596, institutional review board approval of this project is currently pending. Basic information related to human subjects procedures is as follows:

Characteristics of the Subject Population. The subject population will consist of 120 individuals with severe mental problems and their approximately 480 network ties who will be followed through an 18 month period.

Sources of Research Material Obtained. The proposed study will deal with information provided by subjects in response to interviews. Background information of overall clinic usage will be used in the feasibility study. Records are necessary to examine compliance with treatment regimens.

Plans for Recruitment of Subjects and Consent Procedures. Each potential subject will receive a letter informing him/her of their selection for the study. This letter will describe the purpose of the study, the importance of their participation and a telephone number that they can call for more information, to check on interviewers, etc. Depending on treatment regimen, these patients will be contacted by the P.D. or Field Director at home or at the treatment site. They will also be told of the confidential nature of the survey, that their responses identified only by computer identification number; and that their interviews will not be made available to any Clinic personnel or network ties. The interview itself will contain an "informed consent" waiver. Respondents will be given a copy for their records. Focal respondents will also be asked permission to interview their network contacts. The procedure will be repeated for network contacts. Confidentiality will be maintained through a master list of names locked up in file drawers. The process of data gathering in a panel study requires that names, addresses and phone numbers be available but these will be kept separate from the interview schedules which will be identified only by a number. No uniquely identifying information will appear on the interview or be provided to the CSR staff doing the data entry. Interviewers will be instructed not to discuss the content of interviews outside of the Project Staff.

Potential Risks to the Subject. No potential risks to subjects are expected. Potential respondents will not be pressured, in any way, into participating in the study. While participants will be asked to tell the story of their illness, to indicate the number and nature of their network contacts (including conflicts with them), respondents are free to refuse to answer any question asked. Further the Feasibility study will minimize the use of any questions on the final interview schedule which appear to be upsetting. If clients or their network ties become agitated during the course of an interview, interviewers will be instructed to skip to a less sensitive portion of the schedule. If that fails, interviewers will be instructed to terminate the interview and report the occurrence directly to the P.D. In these cases, the P.D. has made provisions to get respondents in contact with appropriate agency personnel.

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APPENDIX I: Eraker et al.'s and Freidson's Models

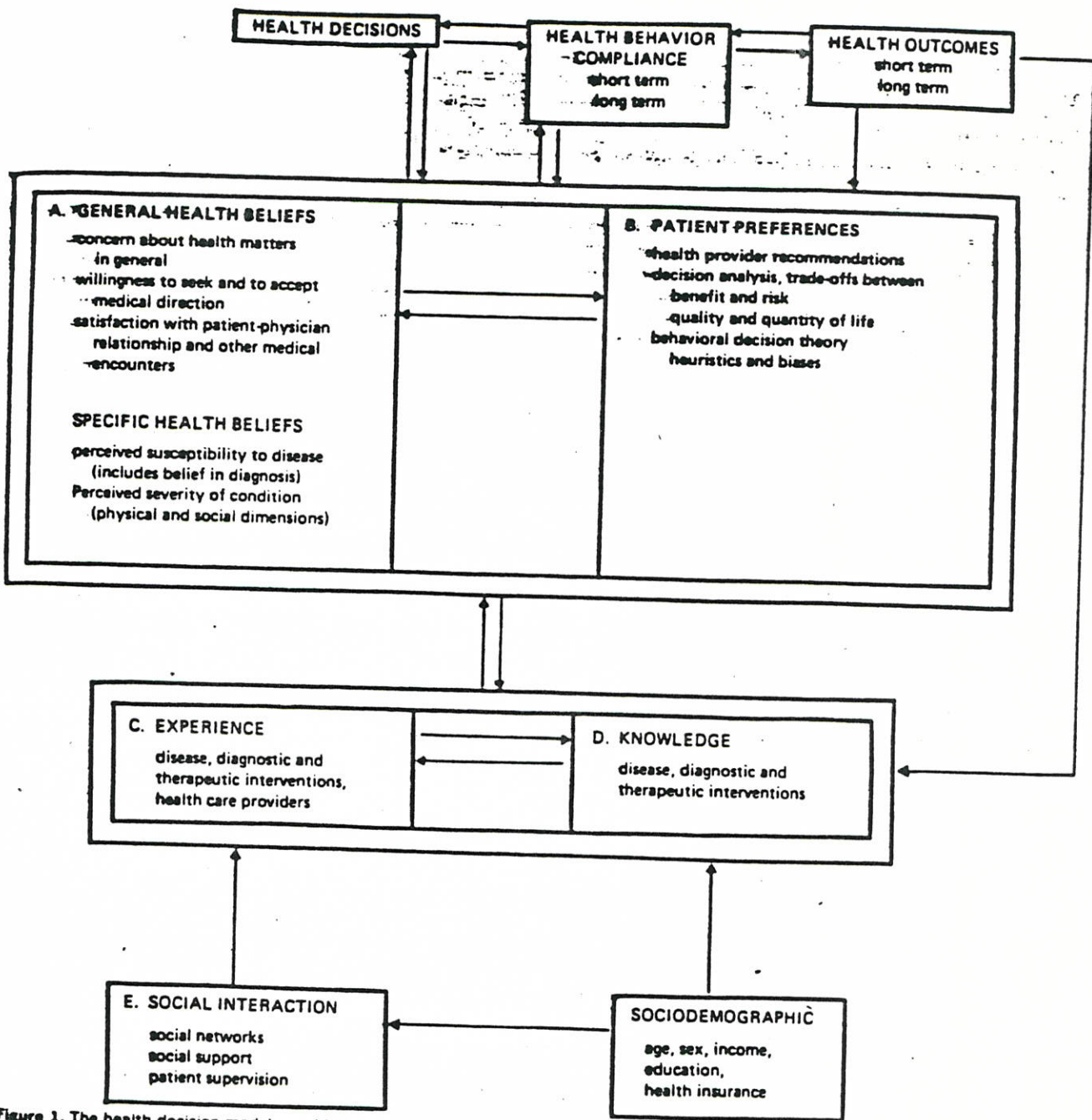


Figure 1. The health decision model, combining the health belief model and patient preferences, including decision analysis and behavioral decision theory.

TABLE 5. PREDICTED RATES OF UTILIZATION OF PROFESSIONAL SERVICES, BY VARIATION IN LAY REFERRAL SYSTEM

<i>Lay Referral Structure</i>	<i>Lay Culture</i>	
	<i>Congruent with Professional</i>	<i>Incongruent with Professional</i>
Loose, Truncated	Medium to high utilization	Medium to low utilization
Cohesive, Extended	Highest utilization	Lowest utilization

FREIDSON'S (1970; p. 294) NETWORK MODEL OF HEALTH CARE UTILIZATION