Understanding the Family Perspective: An Ethnographic Framework for Providing Occupational Therapy in the Home

Laura N. Gitlin, Mary Corcoran, Susan Leinmiller-Eckhardt

Key Words: assessment process, occupational therapy ● caregivers ● dementia ● home care services

This article presents a framework for providing occupational therapy services to family members caring for elderly persons in the home that is based on four key principles derived from ethnographic methodology: identification of an informant, use of an emic (insider) approach, engagement in self-reflection, and interpretation of information. The underlying strategy is to use these principles to derive an understanding of the personal meaning of caregiving, the way in which care is provided, and the specific aspects of caregiving that are problematic from the perspective of the family member. Services are then developed that reflect individual need as expressed by the caregiver and that fit the fundamental values and belief system of the family unit. A case example is presented to illustrate the framework in action in a home situation with family members caring for an elderly person with dementia.

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This article was accepted for publication October 24, 1994.

It has been firmly established that families provide the majority of long-term care in the home to elderly persons with cognitive and physical impairments (Pepper Commission, 1990; Stone, Cafferara, & Sangl, 1987). To support family caregivers in these efforts, there has been an increased interest in developing and testing the effectiveness of a wide range of interventions (Knight, Lutzky, & Macofsky-Urban, 1995) and in identifying the particular contributions of occupational therapy (Clark, Corcoran, & Gitlin, in press; Corcoran & Gitlin, 1992; Hasselkus, 1989). However, the growing body of literature on caregiver interventions has suggested that family members tend to underuse formal health and human services (Knight et al., 1993), may indicate little need for assistance (Collins, 1992; Smyth & Harris, 1993), and sometimes express conflict with the goals that are established by health and human service professionals (Chiou & Burnett, 1985; Hasselkus, 1991; Kaufman, 1988). Furthermore, research on caregiver interventions such as home environmental modifications (Gitlin & Corcoran, 1993; Pynoos & Ohta, 1991), respite, psychoeducational counseling, and support groups has indicated that caregivers are selective in their use of prescribed strategies and do not uniformly benefit or demonstrate reduced stress from participation in these services (Knight et al, 1993).

Recent research in caregiving that has used naturalistic inquiry has demonstrated that caregiving in the home is a complex process that is imbued with meaning and purpose. The meaning of caregiving, or how a person makes sense of his or her experiences, influences how daily care is provided in the home and how caregivers define their needs (Albert, 1992; Gubrium & Sankar, 1990; Hasselkus, 1988, 1989). Other research has noted that caregivers vary in the way they adapt to their experiences and that they identify a range of factors as stressful and cope differently depending upon the particular stressor (Corcoran, 1992; Henderson & Gutierrez-Mayka, 1992; Williamson & Schulz, 1993). These findings underscore the highly individual and unique nature of each caregiving situation. The findings also suggest the existence of a "neglect of perspective" or the disregard by health care professionals of the client's perspective on his or her own needs in developing services (Fine, 1993, p. 2).

Despite the evidence that caregivers define, approach, and react to their caregiving role in distinct ways, occupational therapists lack a framework for developing occupational therapy services that are based on the unique needs of the family members we seek to support. A framework from which to evaluate the specific and individualized needs of families and their elderly members with disabilities is increasingly important as we move toward a health care system that is community and home based.

Recently, there has been an increased interest in ethnography as an approach to research in gerontology.
(Gubrium & Sankar, 1994) and health services (DePoy & Gitlin, 1994), and as a basis for deriving clinical intervention strategies that overcome the potential conflict in perspectives between service provider and client (Hasselkus, 1990; Hill, Fortenberry, & Stein, 1990; Kleinman, 1988; Spencer, Krefting, & Mattingly, 1993). Ethnography is an approach to understanding culture or patterns of behavior and the meaning and interpretation by its participants. The purpose of ethnography is to understand another way of life as it is viewed and given meaning by participants. The ethnographer is interested in the values, meanings, and viewpoints of persons and how persons make sense of or perceive their own context.

It has been suggested that occupational therapists function in a manner similar to ethnographers in that they strive to elicit the client’s perspective and use this information to develop treatment protocols to fit the client’s value and meaning structure. In her 1990 Eleanor Clarke Slagle lecture, Fine stated, “Occupational therapists are ethnographers of sorts. We have unique access to information about activities of everyday living and what it is like to live with an illness or disability. We need only to acknowledge and actualize it” (1991, pp. 500–501). A few occupational therapists have begun to identify how to actualize an ethnographic perspective. Hasselkus (1990) described the value of using ethnographic interviewing techniques as a tool in occupational therapy practice with family caregivers. Spencer et al. (1993) also suggested that constructs derived from ethnography are relevant and useful to occupational therapy and offer an important approach to practice.

Building on these works, we have developed a framework for evaluating the needs of family caregivers that uses concepts from ethnography. This framework is intended to advance the efforts of occupational therapists to evaluate the caregiver’s inner life as a basis from which to make treatment decisions and derive an individualized service approach in the home (Fine, 1993). It incorporates four key terms from ethnography (informant, emic, reflexivity, and interpretation) and the principles they reflect. The strategy is to use these principles and the actions they represent to derive an understanding of the perspective of the family member, the personal meaning of providing care, how care is provided in the home, and specific aspects that are perceived to be problematic. Specific occupational therapy strategies are then constructed that fit the fundamental values and belief system of the family unit or social-cultural context of the home.

This ethnographic framework has evolved through a number of funded research and training programs awarded to the first two authors. These programs have developed and evaluated the use of this framework under a number of conditions. Systematic case analyses involving family members caring for persons with disability suggest that occupational therapy intervention strategies are integrated into family routines and effectively used when occupational therapists use these principles to guide treatment. The outcomes of this research (Corcoran & Gitlin, 1992; Gitlin & Corcoran, 1993) as well as a description of a training approach based on some of these principles (Gitlin & Corcoran, 1991) have been reported elsewhere.

We examine the four key principles constituting the framework, their ethnographic foundations, and their clinical applications. A case example illustrates the framework in action in a home situation with family members caring for a person with dementia.

### Four Key Principles Of Ethnography

The four key principles of this framework, which are outlined in Table 1, are designed to enable an occupational therapist to modify traditional practice and evolve treatment strategies that target the values and meaning of the caregiver or family unit. These principles are not to be thought of as linear, step-by-step procedures for evaluation. Rather, they form a framework, or way of thinking about the caregiving situation, and can be used in combination with formal evaluations that are traditionally conducted in the home.

#### Principle One: Identify an Informant in the Home

As shown in Table 1, the first term in ethnography that is relevant to service delivery is that of identifying an informant or informants. In ethnographic methodology, an informant is a person with knowledge of the cultural system who informs the ethnographer of the values, beliefs, and activities of the group that is being studied. This person is a key source from whom the ethnographer learns about daily practices and behaviors and gains insight into the meaning of an activity or routine.

The clinical application of the term informant involves the principle of viewing the family member or primary caregiver as a lay practitioner. Hasselkus (1988) has used the term lay practitioner to refer to caregivers because of their primary role in managing, coordinating, and providing hands-on care to older adults with impairments.

#### Table 1

<table>
<thead>
<tr>
<th>Ethnographic Principle</th>
<th>Definition</th>
<th>Clinical Application</th>
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<tbody>
<tr>
<td>Informant</td>
<td>Individual with knowledge</td>
<td>Lay practitioner</td>
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<tr>
<td>Emic</td>
<td>Insider perspective</td>
<td>Uncovering personal meaning</td>
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<tr>
<td>Reflexivity</td>
<td>Self-reflection</td>
<td>Treatment planning Hypothesis development Hypothesis testing Self-questioning</td>
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ment. Through the act of doing and trial and error, family members develop a practice style, gain knowledge, and develop expertise or wisdom in providing care. Smith and Baltes have defined wisdom as “expert knowledge” about “fundamental life matters.” (1990, p. 495) Applied to the case of caregiving, wisdom or expert knowledge of the pragmatics of providing daily care evolves over time as lay practitioners develop knowledge of how to perform caregiving tasks. This knowledge is situation specific and reflects a professional’s know how as opposed to his or her formal or theory-based knowledge (Albert, 1992; Benner, 1984).

As an informant, the lay practitioner is an important source of information about caregiving routines and priorities of both the caregiver and the family member who is impaired. By viewing family members as practitioners, an occupational therapist recognizes their pivotal role and responsibility in the caregiving situation and their ultimate control over what therapeutic strategies evolve and are adapted. This principle encourages the occupational therapist to view his or her own role as that of an enabler as opposed to a prescriber.

Principle Two: Use an Emic Approach

The second principle is the use of an emic approach, that is, obtaining an insider perspective or the point of view of an informant as to how things are and why. In an ethnographic framework for service delivery, the occupational therapist interviews and observes the lay practitioner(s) to identify their perspective of the meaning that shapes their act of caregiving. This step is done in an effort to gain the family members’ perspective and identify the unique meaning they have assigned to caregiving. Although a wide range of questions may be useful to gain an insider perspective, those included in Section I of the Appendix are straightforward and simple. They enable a caregiver to begin to tell the story of his or her caregiving experience. Other techniques to learn the inside view include observation of the physical environment, observation of a caregiving task, and active listening to how the lay practitioner constructs his or her story of the caregiving situation. Observation of the home environment in traditional occupational therapy evaluation typically focuses on accessibility and safety. In an ethnographic approach, observation is expanded to include how caregivers set up objects for daily routines, the presence of photographs and other objects of meaning, and the extent to which caregivers have rearranged the home to accommodate the level of competence of the family member who is impaired.

Principle Three: Engage in Self-Reflection

The third principle is a dynamic activity in which the ethnographer engages in self-questioning in an attempt to understand the relationship of his or her own values and beliefs to those that exist in the cultural setting of the home. Through this constant comparison between the investigator’s expectations and the way things are, insights are gained. Likewise, in working with a lay practitioner to identify and understand meaning, the occupational therapist remains reflexive or self-questioning and continually asks himself or herself four questions: (a) What do I see happening in this home? (b) Do I understand the perspective of the family members? (c) Is my vision of the family members’ needs the same as those of the lay practitioner(s)? (d) In what ways are my values in this caregiving situation the same or different from those of the lay practitioner(s)?

Keeping notes as to one’s own personal reactions to the caregiving situation, as well as one’s discoveries, facilitates the reflexive discovery process. Through the act of self-reflection, the occupational therapist advances his or her own understanding of the family members’ perspective and begins to formulate initial hunches or hypotheses about the meanings that underscore the actions of these lay practitioners. These initial hypotheses form the basis from which treatment planning emerges. As treatment progresses, the therapist continually tests these initial hypotheses by comparing observations of the family members’ actions during treatment to his or her interpretive framework, discussed in Principle Four.

Principle Four: Develop a Framework for Interpreting Information

The fourth principle is based on the interpretive method used in ethnography. The interpretive process involves deriving an analytic framework from which to understand and explain behaviors and phenomena. Through interpretation, the ethnographer attempts to make sense of what is observed and uncover the underlying meanings and beliefs that guide behavior.

Likewise, the occupational therapist, on the basis of interview, observation, active listening, and reflexivity, derives an interpretation or analysis of the emic perspective, or how things work and what is important for the lay practitioner. Interpretation is a fluid, dynamic process by which the therapist continually refines his or her understanding of the family members’ perspective on the basis of incoming information. The interpretative process is comparable to the clinical reasoning process by which a service provider attempts to fit the pieces together in the form of an effective treatment plan and its implementation (Fleming, 1991). In an ethnographic framework, the clinical reasoning involves skill in interpreting the meanings that underscore the family system and skill in adapting treatment strategies to fit the particular system of meaning of the family unit. To refine an interpretive framework, the occupational therapist constantly observes the family members’ behavior and returns to three
fundamental questions: (a) What does the disability or impairment mean to the care receiver and the family member? (b) How do the family member and care receiver experience the caregiving activity? (c) On the basis of the underlying meaning that informs care, what is an appropriate treatment strategy to support the efforts of the family unit?

Refinement of the interpretive framework begins with the initiation of a home visit and does not end until the termination of treatment. As strategies are introduced, the occupational therapist evaluates how they are received and the extent to which they are incorporated into daily caregiving routines. Those strategies that are rejected by family members provide important information to the occupational therapist as to the beliefs and practices of the lay practitioner(s). Strategies that most closely match the beliefs and self-defined needs of family caregivers are those that will be embraced by family members and used effectively.

As displayed in Figure 1, this ethnographic framework for service delivery leads to the development of an individualized treatment approach. It uses a dynamic, iterative process, as in ethnography, in which treatments evolve and are continually refined in light of the observations and interpretations that are derived.

Case Example
A case example illustrates the four principles described previously as used in a five-visit occupational therapy intervention protocol with family members caring for an elderly person with dementia in the home. A detailed description of the intervention protocol has been published elsewhere (Corcoran & Gitlin, 1992; Gitlin & Corcoran, 1993).

In this case, there were two informants, or lay practitioners. Mrs. P, a frail, 90-year-old spouse, and her 85-year-old sister resided together in a two-story, twin home critical for the well-being of both the care receiver and the caregivers. Each suggestion, however, was rejected by the family members, and used effectively.

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Figure 1. Ethnographic framework for service delivery.

The occupational therapist began to realize that Mrs. P and her sister rejected these suggestions because they presented a dramatic change to the daily routines and image of the household that they had constructed. In addition, these recommended interventions reflected only the formal provider perspective that focused on the medical and dysfunctional aspects of the situation. The occupational therapist recognized that she had an incomplete understanding of the meaning underlying the actions of the family members, the therapist initially offered recommendations to enhance safety and decrease caregiver stress. These initial recommendations included: (a) the use of formal home care services to assist in activities of daily living, (b) the implementation of major home adaptations such as installing a stair glide or moving Mr. P's bed downstairs to the dining room for safety, (c) medical intervention for Mr. P's poor nutritional status, (d) day care participation for Mr. P, and (e) preparation for the possibility of nursing home placement for Mr. P. These recommendations, which represent standard practice, were considered by the occupational therapist as critical for the well-being of both the care receiver and the caregivers. Each suggestion, however, was rejected by the lay practitioners (the caregivers).

Strategies to Understand the Caregivers' Perspective
The occupational therapist began to realize that Mrs. P and her sister rejected these suggestions because they presented a dramatic change to the daily routines and image of the household that they had constructed. In addition, these recommended interventions reflected only the formal provider perspective that focused on the medical and dysfunctional aspects of the situation. The occupational therapist recognized that she had an incomplete understanding of what was meaningful in this household and began to use several techniques to discover the beliefs and values that informed decision making by the
lay practitioners. She observed how objects were used in the home and the way caregiving tasks were performed, and she more closely listened to the language used by the lay practitioners to describe their daily routines. For example, the therapist noted that care objects in the home, such as a walker and commode, were kept out of sight until they were required. There were no signs or visual cues to encourage Mr. P’s participation in basic self-care tasks, and the environment was not simplified to enhance his competence. As a consequence of the process of observing objects and behaviors, testing emerging hypotheses as to what was occurring in the home, and self-reflection over several home visits, the occupational therapist gained a better understanding of the emic perspective and a feasible, interpretive framework from which to develop specific, relevant solutions to fit this particular case.

**Emic Perspective**

The essential meaning of the caregiving activities for these two frail women was to maintain a sense of normalcy, or consistency, with the way things were before the onset of Mr. P’s dementia. Their primary concern in providing care was to preserve or maintain a sense of continuity in Mr. P’s role in the home. From the perspective of Mrs. P and her sister, normalcy meant getting Mr. P through his daily routines of self-care, stair use, and eating as they had always done with minimal changes so as to preserve an image of what Mr. P used to do and how he used to be. The importance of maintaining normalcy and Mr. P’s previous biographical roles were reflected in their stoic determination to enforce the basic routines that had always been followed in their adult lives, the language they used to describe their difficulties in the caregiving situation, and the types of caregiving concerns that they identified. For example, they preferred to label Mr. P’s behavior as “uncooperative” in daily routines and rejected medical terms that suggested that Mr. P was unable to behave competently because of the underlying pathology. They were concerned about his poor eating habits primarily because these habits upset their meal routines. They also identified Mr. P’s uncooperative behavior and stiffness when descending the stairs as a concern because it interfered with their expectation that he sit in the living room at a specific point in time during the day, as he used to do.

Mrs. P had rejected the occupational therapist’s initial recommendations based on her wish to preserve her image and understanding of who Mr. P was and what he had liked to do. As she pointed out, Mr. P was never one to participate in groups and therefore he would not like a day care situation or nursing home. Whereas the occupational therapist had been concerned with the physical well-being of the caregivers and the medical status of the care receiver, the lay practitioners chose to preserve and be concerned with the biographical status of Mr. P and to value the preservation of this status.

**Interpretation**

Through observation of daily tasks, open-ended interviewing, and reflexive self-questioning that occurred over all five home visits, the occupational therapist was able to derive an emic understanding and an interpretative framework of normalization for this particular family (Robinson, 1993). Individualized treatment strategies emerged from an iterative process that was based on continual evaluation of things observed and said, self-reflection of the therapist’s own values and concerns, and refinement of the therapist’s interpretive framework.

The therapist validated and tested her emerging interpretations of the caregivers’ need to preserve Mr. P’s roles and a sense of normalcy by asking the caregivers validating questions, such as “Is this how you see it?” This technique invited the lay practitioners to comment on the accuracy of the therapist’s hypotheses and understandings of what was meaningful and important to them. The therapist began to use the language of the lay practitioners to discuss what was happening in the caregiving situation and affirm their perspective. This communication required avoiding the use of medical or professional terminology and reframing problems with the vocabulary of the caregivers. An example was the use of the term “uncooperative” when describing Mr. P’s actual inability to participate in life tasks.

On the basis of the meaning of caregiving in this home, the occupational therapist was able to offer a number of solutions to caregiving problems that were acceptable to the lay practitioners. The challenge to the occupational therapist was to uphold the biographical image of Mr. P while easing the lay practitioners’ stresses and safety risks in performing caregiving tasks. In order to effectively communicate about caregiving strategies and routines, it was important for the therapist to link suggestions to the lay practitioners’ goal of making Mr. P more “cooperative.” Suggestions that fit this framework involved what may appear to be small changes in technique or routine (e.g., allowing Mr. P to initiate descending the stairs with the lay practitioners walking on either side, involving other family members to provide respite for the caregivers), minor home modifications for safety, and incorporation of techniques that enhanced Mr. P’s role performance (e.g., use of visual cues, finger foods, and simplified instructions during eating). These modifications were accepted by the lay practitioners and easily incorporated in the routines that they had established long ago and sought to maintain. These solutions were acceptable because the occupational therapist framed them in terms of how well they maintained Mr. P’s role as a family member and status as an independent person. In addition, these solutions did not change valued routines.
Implications for Occupational Therapy

From an ethnographic point of view, informal caregiving represents a cultural activity in that it has meaning to its participants and reflects the caregiver's values and beliefs about the person and his or her disability. In an ethnographic framework for service delivery, a health care professional suspends his or her own values and beliefs as to the appropriate course of treatment in an effort to discover what actually goes on in a family that is providing care and the value and meaning that underlies these activities. The four principles provide a framework to guide the clinical reasoning that needs to occur in working with lay practitioners. Mattingly and Fleming (1994) have asserted that a primary and challenging feature of clinical reasoning in occupational therapy is distinguishing the nature of the good for each particular client. The good refers to an image of what is beneficial and healthy for each client and is directed partially by the meanings assigned to the disability by the client. Occupational therapists are acutely aware of the need for knowledge about their clients' meaning structures (Fleming & Mattingly, 1994) and the difficulties associated with evaluating these perspectives accurately (Fine, 1993; Spencer, 1993). The ethnographic framework for evaluating the family members' perspective presented in this article can serve as a helpful structure for integrating the client's psychosocial, physical, and emotional dimensions in treatment planning. It can be used in combination with traditional formal assessment instruments of cognition, function, or health status, and can enable occupational therapists to gain insight into distinct caregiving practices and how these practices are embedded in the social and cultural context of the family unit.

An important implication of this framework for occupational therapy practice lies in its usefulness for identifying and addressing client-therapist ethical conflicts. Differences in priorities about the focus of treatment has been identified as a major form of ethical dispute between client and therapist (Corcoran, 1993; Gitlin, 1993; Hasselkus, 1991). For instance, Hasselkus (1991) noted that the principle of autonomy (listed first in the Occupational Therapy Code of Ethics [American Occupational Therapy Association, 1991]) may conflict with a client's cultural belief that one's elder is entitled to be dependent.

The case of Mrs. P illustrates our discomfort with these ethical dilemmas. For example, Mrs. P and her sister chose to uphold their biographical image of Mr. P as an independent, functioning husband who participated in daily routines, and they rejected the use of medical terms to describe the caregiving process. That is, they chose to continue practices such as his stair climbing at the risk of great personal injury. In this case, the occupational therapist needed to respect the lay practitioners' need to uphold these biographical notions even though the frailty of the caregiving situation remained disconcerting for her. Use of an ethnographic framework will not only help the therapist identify and validate the client's beliefs about disability, but also to continually explore the nuances of his or her own belief structure through the process of reflexivity.

An ethnographic framework for interviewing and service delivery is unlike a medical model approach and will therefore feel different to an occupational therapist in several ways (Levine & Gitlin, 1990). First, the family member as a lay practitioner is viewed as a partner in determining the most appropriate way of approaching the caregiving situation. This approach has the effect of empowering and reassuring family members while helping service providers to relinquish control. Second, intervention strategies are not dictated but evolve from interactions that reflect a blend of formal and practical knowledge. Third, decisional control to adapt new caregiving strategies or coping styles resides with the lay practitioner, whereas the service provider needs to remain flexible. Fourth, service providers must develop a different measure of success that includes the family members' acceptance and modification of suggestions to fit their situation.

Conclusion

The framework presented here is in direct contrast to the medical model approach in which standard treatment protocols emerge according to the condition, its pathology, considerations of dysfunction, and the assumption of the caregiving situation as a universal stressor. The intent of the framework presented here is to enable the occupational therapist to think beyond what ought to be done in a home care situation to understand and respect what family members' themselves emphasize as valued practice. It provides a systematic way of thinking about occupational therapy practice with caregivers and shaping the clinical reasoning process in home-based occupational therapy.

The framework also has potential application to other practice areas in the profession of occupational therapy. For instance, therapists specializing in pediatrics
may find that an ethnographic framework augments their efforts to collaborate with parents of children with disabilities. Likewise, occupational therapists practicing in the fast-paced arena of acute care may gain a useful way to establish the priorities of treatment and determine relevant discharge plans for their short-stay clients. Although this framework focuses on the caregiver, a similar process can be used to understand the perspective of the care receiver and how it may differ from that of the caregiver. In addition, the elements of this framework are appropriate for home care situations in which the person who is impaired is the primary receiver of service.

As our health care system undergoes dramatic revisions, the focus will be increasingly aimed at delivery of quality care in the community. Understanding individual perspectives and the unique meanings of the caregiving experience is critical to the development of services that are effective in assisting the family members in their ongoing caregiving efforts. Our experiences suggest that caregivers are receptive to the knowledge and skill of formal providers when this knowledge and skill is transmitted in a manner that is consistent with the beliefs and values of the family unit.

Appendix

Examples of Useful Questions

I. To obtain meaning, ask lay practitioner:
- What is a typical day like for you?
- What most worries or concerns you?
- How is it now versus before?
- Tell me how you manage your day?
- What are your feelings about the future?
- What are some of your successes?

II. To verify meaning, ask lay practitioner:
- Is this how you see it?
- So you are saying that when ___ happens, you get frustrated. It sounds as though that really upset you.

III. To think reflexively, ask yourself:
- What do I see happening in this home?
- Do I understand the perspective of the family members?
- Is my view the same as the lay practitioner(s)?
- In what ways are my values in this care situation the same or different from those of the lay practitioner(s)?

IV. To derive an interpretive framework, ask yourself:
- What does the disability or impairment mean to this person and the family member?
- How does the family member experience the caregiving activity?
- On the basis of an understanding of meaning, what is an appropriate treatment strategy to support the efforts of this family unit?

Acknowledgments

The framework presented in this article was developed on the basis of research supported by the National Institute on Disability and Rehabilitation Research (Grant No. H133G00160). An earlier version of this article was presented at the Mental Health and Aging Symposium, Wills-Jefferson Hospital, Geropsychiatry, Philadelphia, Pennsylvania, October 29, 1993.

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