Leisure Activities After a Stroke: An Ethnographic Approach

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Ethnography is a qualitative research design that has relevance for clinical research in occupational therapy. The ethnographic approach is illustrated in the present paper through a description of how it could be used to investigate the effectiveness of an occupational therapy leisure intervention with stroke survivors. This paper contrasts ethnography with a randomized clinical trial design addressing the same question. Background information about ethnography, its relationship to other qualitative approaches, and its relevance to occupational therapy is addressed. Additionally, specific aspects of the research process are described, including triangulation of data-gathering strategies, sampling, and analysis. The limitations of ethnography are then described. The paper concludes with some examples of ethnographic work with persons with disabilities.

Definition of Ethnography

In its broadest sense, ethnography is the work of describing a culture. Culture is a process of behavior and communication that has been learned by a person in the context of his or her experience (Krefting, 1990). Persons that share a similar sociocultural context will have similar, though not identical, patterns of behavior and communication. The object of ethnography is to allow one to understand another way of life from the participant’s viewpoint by systematically observing, detailing, describing, documenting, and analyzing the daily lives of persons in a culture or subculture (Leininger, 1985). Ethnography incorporates the knowledge gained from the people in a particular culture in addition to the knowledge gained about them. It engages an inductive method that generates research questions rather than answering predetermined ones. (For background information on the qualitative perspective by occupational therapists, see Kielhofner, 1982a and 1982b; Krefting, 1989a; Littler, 1989b; Maguire, 1989a; Saladino, 1989a; and Schalock, 1989a.)

The purpose of this paper was to illustrate the nature of ethnography through a discussion of how the research question posed by Jongbloed and Morgan in this issue of the American Journal of Occupational Therapy (AJOT) (pp. 420–427) could be investigated with an ethnographic approach. In Jongbloed and Morgan’s article, a randomized clinical trial was used to address the problem of documentation of the effectiveness of an occupational therapy leisure intervention with stroke survivors. The present paper describes how ethnography can be used to generate and describe relevant variables in leisure participation in stroke survivors and to identify environmental factors critical to the success of occupational therapy intervention.

First, we present some background information about ethnography, its relationship to other qualitative approaches, and its relevance to occupational therapy. Next, we suggest the advantages of ethnography in relation to leisure participation and persons with stroke. Note that we are not proposing a single study that would address the identical research question posed by Jongbloed and Morgan, but rather, we suggest a number of ways that ethnography can elucidate the relationship between leisure participation, occupational therapy, and persons with stroke. We then identify some specific aspects of the research process in the proposed ethnographic study, including triangulation of data-gathering strategies, sampling, and analysis. The limitations of ethnography are then described. The paper concludes with some examples of ethnographic work with persons with disabilities. We do acknowledge Jongbloed and Morgan’s contribution; the publication of unpredicted results or findings that do not support the hypotheses are valid and valuable contributions to the occupational therapy knowledge base.
of the daily events of peoples’ lives in their own words. Although these designs have a similar philosophical base, they differ in the way that they are conducted.

**Phenomenology.** Phenomenology asks what it is like to have a particular experience. It is based on the assumption that human behavior goes beyond that which can be observed; its significance lies in the perspectives and meanings held by the person in a particular context (Schmid, 1981). Understanding arises both from observation of behavior and from information about the person’s interpretations of his or her own experiences. Phenomenological research is often used to sensitize readers to an experience, that is, to promote the understanding of the particular experience under study. It is done through the gathering of extremely detailed descriptive information based on intense researcher-informant relationships with relatively few people. The informant’s feelings, thoughts, perceptions, beliefs, and experiences are all critical units of analysis. Hasselkus and Dickie (1990) provided an example of a phenomenological perspective in their pilot study of the experience of satisfying practice among occupational therapists. Although this study was not a full-scale phenomenological project, the researchers used the critical-incident strategy to gather data, which they analyzed from a phenomenological perspective. Full-scale phenomenological studies are more common in nursing, for example, Bergum’s (1988) study of the experience of childbirth.

**Grounded theory.** Grounded theory is an inductive approach to theory generation whereby complex social processes are described. It is an exploratory qualitative research approach (Glaser & Strauss, 1967) by which conceptual models and hypotheses follow from the analysis of the data rather than precede it, as in traditional quantitative studies. Data are collected through participant observation and interviews so as to generate categories of data for theory construction. Whereas phenomenology is a specific research strategy, grounded theory is more an approach to analysis and may be combined with other approaches, such as ethnography. An example of the use of grounded theory in the occupational therapy literature is Fondiller, Rosage, and Neuhaus’s (1990) exploratory study of values that influenced the clinical reasoning process in occupational therapy. In Fondiller et al.’s study, fellows of the American Occupational Therapy Association (AOTA) were interviewed about a standard case study, and categories and groups of values about practice were derived from the interview data. These categories and groups of values were then described in terms of the evolving model of clinical reasoning.

**Ethnography.** Ethnography is a generalized approach to a phenomenon that focuses broadly on cultural description. It allows for the examination of a particular experience, such as disability, within the cultural context. It differs from phenomenology in that it takes a broader perspective that involves consideration of the political,
economic, and sociocultural context of the daily lives of a larger number of informants. It is also often more dependent on participant observation as a data-gathering technique. Ethnography is the most common type of qualitative research strategy used in the occupational therapy literature; examples include Kibele and Loren’s (1989) work with adults with cerebral palsy, Hinojosa’s (1990) study of mothers of children with cerebral palsy, Kielhofner’s (1981) work with deinstitutionalized adults with developmental delay, Hasselkus’s (1988, 1989) research on adult caregivers of persons with dementia, and the first author’s research on brain injury (Krefting, 1989b).

An Ethnographic Approach to Leisure Activities After a Stroke

Jongbloed and Morgan used a randomized clinical trial approach to investigate the effect of occupational therapy intervention on leisure activities of stroke survivors. This approach is one of the most rigorous ways by which one can determine treatment effect in health care research (Payton, 1988; Riegelman, 1981). In their discussion of the findings, Jongbloed and Morgan concluded that they did not have sufficient knowledge of the factors that influence leisure activity to use the experimental design and suggested that an ethnographic approach would have been a better first step.

The literature on leisure and recreation supports the use of the qualitative approach for the study of leisure activities. Glancy (1986) noted that this approach has been used to investigate a number of sociopsychological concepts in relation to leisure, including social roles, attitudes, social context, and leisure-related values. Howe (1985) argued persuasively for a qualitative research approach in the study of leisure, noting it is not just what people do but how they do it and what it means to them that is important to researchers. Downing (as cited by Glancy) suggested that aggregated data do not always communicate the implication underlying leisure choice and satisfaction. Glancy’s study of the sociopsychological aspects of group sport membership is a good example of an ethnographic approach to leisure. She used participant observation and personal accounts to investigate the issue of competitiveness and social relations and concluded that ethnographic methods would be valuable in studying leisure patterns within the family, peer-group, and life-cycle contexts.

Rationale for Ethnographic Research on Leisure in Persons With Stroke

The use of an ethnographic approach to investigate the research question of leisure among stroke survivors is supported for several reasons. First, not all is known about the nature of leisure in this population; important variables remain unidentified. A clinical trial is a rigorous design only as long as the appropriate variables have been identified. In this sense, ethnography would involve first-stage exploratory research to identify the factors that may then be studied with a quantitative approach. Ethnography, in this case, is used to generate hypotheses or variables rather than test them. This exploratory aspect of ethnography is also seen in the use of grounded theory analysis, in which a new conceptual framework can be developed and tested.

It is important to note that this type of exploratory ethnography is often thought of as less rigorous than the quantitative research designs that follow and that it is only useful for the generation of variables or constructs. Ethnography is also critical in the development of knowledge in its own right. For example, ethnography is useful when the subjective, or insider, approach is required, as in the determination of a client’s need (see, for example, Kibele’s [1989] work with adults with cerebral palsy and the first author’s [Krefting, 1989b] work with persons disabled by traumatic brain injury). Ethnography is also useful in the study of new phenomena, such as the effects of the HIV virus or the late effects of polio.

Jongbloed and Morgan’s recommendation of an ethnographic study based on the results of a clinical trial suggests that ethnography is not always conducted as the first phase of a research program, that it can follow a study that uses an experimental or quasi-experimental design. Stubbins (1984) identified another advantage of ethnographic research in that it helps professionals to control the biases they often develop during their training. Because ethnographers begin with broad research questions rather than specific, operationalized hypotheses, they are less likely to overlook phenomena that do not fit their original expectations, which are most often based on their professional socialization. Jongbloed and Morgan acknowledged a number of alternative explanations for their result that might have been identified more clearly with the use of ethnography, for example, the importance of social relationships. In this case, an ethnographic approach might have helped the researchers develop new insights or perspectives at the beginning of the research program, thus leading to a stronger study design.

Jongbloed and Morgan identified a second reason for the use of an ethnographic approach regarding stroke and leisure—the need to investigate environmental factors. One of the strengths of ethnography is that it focuses on the informant’s interaction with the social and physical environments. Borg and Gall (1979) noted that ethnographic studies provide a complete picture of the person and his or her physical and sociocultural environment, in contrast to traditional research, which often focuses on a small number of discrete, narrowly defined variables. In discussing the results, Jongbloed and Mor-
gan concluded that environmental factors may exert a stronger influence on involvement in and satisfaction with leisure than does occupational therapy intervention. The researchers postulated that these factors might include access to recreational pursuits and funds, architectural barriers, and family support. Ethnographic research would verify their postulations and identify other environmental factors.

A third reason for the use of ethnographic research is that the instruments used by Jongbloed and Morgan (Level of Free-Time Activities and Level of Satisfaction with Free-Time Activities from the Katz Adjustment Index [Katz & Lyerly, 1963]) may have limited the amount of information about leisure activity learned in the study. For example, the 26 leisure activities included in the instrument may not have been relevant to the study sample and may have excluded informants’ major areas of leisure activity. Further, although the Katz Adjustment Index categorizes reasons for not doing the activity as physical, psychosocial, and environmental limitations, an ethnographic approach would gather more descriptive information than these three categories allow.

Ethnographic studies often produce unanticipated benefits in addition to those related to the particular focus of research. One of the strengths of ethnographic research is that it yields the types of information that can be helpful for decision making in health care. Although quantitative studies present descriptive summaries, the numbers and labels of hard science tell little of who the persons with disabilities are and how they experience their lives. Rice (1990) suggested that although some research gives us statistics, we need to look at the human lives these statistics represent, that is, to hang flesh on the statistical bones. Ethnographic studies considering the daily experience of persons with disabilities can provide detailed accounts for those persons responsible for making policy decisions, thus allowing them an opportunity for more informed decisions. In applying this to Jongbloed and Morgan’s study, although an ethnographic approach would generate hypotheses and variables for further study, the descriptive data of the daily lives of persons with a stroke might serve to support a proposal for the development of more community-based occupational therapy services for this group.

Ethnographic data may play a similar educational or sensitization role regarding leisure in stroke survivors in relation to educating students about the diversity of possible outcomes after stroke, thereby illustrating that clients are more than a diagnostic category. Ethnographic data highlight the broad range of responses so that the results represent human variation, not simply the average or mean experience of stroke. This depth and variety of data allows the reader of an ethnographic research report to understand the details of persons’ lives. Importantly, such information also aids in the humanizing of stereotype types of persons with disabilities.

Strategies for Conducting Ethnographic Research on Leisure and Persons With Stroke

A number of strategies could be used in the ethnographic approach to leisure activities with survivors of stroke. Participant observation of people during leisure activities at different times of the day and week and with different groups of people would be a key strategy. Although Jongbloed and Morgan used a therapist to set up leisure appointments, to accompany subjects on a first visit to a leisure program, or both, extensive participant observation is needed to uncover variables that influence leisure activity in stroke survivors. Unstructured interviews about past leisure activities and plans for future activities would also yield factors related to leisure activity. A variation on this is the use of a focus group (Morgan, 1990), in which a small number of informants discuss the issue of leisure. This interactive approach often combines different types of informants in the same group.

Document review is another strategy, which in most research is limited to a literature review of peer-reviewed, indexed health care journals. Ethnographers’ sources of documented information are varied, however, and can include newspapers and magazines; official reports and documents; published biographies and autobiographies; autobiographical material from study informants, such as journals and photographs; diaries and journals; and promotional literature from support and advocacy groups. In the proposed ethnography, autobiographies of persons who have survived a stroke, for example, the poet and novelist Mary Sarton (1988), would provide data for the leisure study. Another source of data could be essays written by informants on specific topics related to leisure, for example, the informant’s most satisfying experience of leisure before and after the stroke. We have found that short essays or tape-recorded reminiscences are powerful adjuncts to direct interviews and participant observation.

Triangulation

The discussion above suggests the need for the adoption of multiple methods by which to gather ethnographic data. The use of various data sources and theoretical perspectives is called triangulation. This method has two advantages. First, it allows the researcher to assess data-gathering strategies against each other in order to cross-check data analysis and interpretation. That is, information from one source is verified with at least one other source. Second, it can contribute additional information that may be unobtainable from a single approach.

Triangulation can include a broad range of research activities. It is most often seen in the use of different data-gathering methods in a single study. For example, the proposed study might use data gathered from a leisure checklist, participant observation, review of biographic
data, focus groups, and key informant interviews. The obtainment of multiple perspectives is also possible through triangulation of investigators (i.e., the use of a research team rather than a single investigator) and theoretical triangulation, in which different theoretical perspectives are used to analyze and interpret data. One could consider the leisure data from a model of occupational performance, disengagement, or health promotion, for example. Triangulation of data sources is a strategy that is often neglected and involves participant observation of leisure activity at different times (e.g., different days, weeks, or seasons), in different spaces (e.g., in the home, garden, community center, or senior center), and in the company of a variety of persons (e.g., among family members, recreation directors, or friends). Interviews and focus groups with family members, particularly spouses, would also be important in an ethnography of leisure with stroke survivors, because one of the principles of ethnographic research is that the unit of analysis include relevant members of the key informant’s social network.

Sampling

Two types of samples commonly used in ethnographic research would be appropriate for the proposed study — purposive, or theoretical, samples and nominated samples. In a purposive sample, the researcher first chooses informants with a broad perspective of the issue being studied (Morse, 1989b). As the study progresses and more detailed information is needed, participants with particular viewpoints are sought, for example, stroke survivors who have returned to competitive status in a leisure activity, such as a master’s swimmer. Informants with atypical experiences are also sought in purposive sampling to reflect the diversity of experiences and possibilities. This might include a person who has no apparent physical or cognitive deficits after a stroke but who no longer participates in any leisure activities.

Participants in a nominated sample are obtained with the use of informants in the study to help identify and recruit other informants. For example, participants in the study might suggest names of other persons from the senior’s center who would be interested in the study. Groups such as the Stroke Family Support Group may be the researcher’s first contact. Such a group would then refer informants. This type of sampling is based on the fact that those persons being studied would recognize other informants because of their shared experience.

Analysis of Ethnographic Data

The analysis of ethnographic data depends on the type of data collected. The units of analysis most common to ethnography are linguistic expressions and observations that can be analyzed with a number of frameworks, including ethnomethodology (Spradley, 1979), sociolinguistic analysis, and metaphorical analysis (Amara-Singham, 1984). Ethnographic analysis, in all its forms, differs from quantitative data analysis in that the former is a cyclical process, that is, data are continually analyzed and then compared with new data as they are collected.

In addition to its cyclical nature, ethnographic analysis is conducted on multiple levels. At a basic level, content analysis reveals repetitive themes within the data. In the proposed study, such themes might include clumsiness, lack of transportation, boredom, and lawn bowling. These substantive themes are then integrated and form the basis of a conceptual or theoretical analysis of data. Higher levels of analysis would reveal such concepts as loss of self-efficacy, environmental inaccessibility, and motivation. Time in the field and immersion in the data help the themes to emerge in the researcher’s mind.

One of the challenges of analysis of ethnographic data is the aggregation of data from multiple informants, documents, and observations. Although analysis seems simple, it is a time-consuming process that requires special training by an experienced researcher and cross-validation. Ethnographic analysis has been simplified with the development of computer packages such as Ethnograph (Seidel, 1985), which help manage the data. These programs do not, however, do the analytical work on the data: Their function is to organize data into a manageable form.

Reflexivity

One of the critical types of analysis used in ethnography is reflexive analysis. Reflexivity is the influence of the investigator’s own background, perceptions, and interests on the ethnographic process (Good, Herrera, Good, & Cooper, 1985) and is similar to the idea of experimental bias. Reflexivity involves the effect of personal history on social research and reflects the idea of the researcher as an instrument. In this sense, the research activities as well as the researcher’s observations, questions and responses in conversation, and choice of informants are all affected by the researcher’s biases and attributes. Part of the ethnographic process is the analysis of the ethnography in the context of the researcher. This is usually done through the compiling and analyzing of a field journal, debriefing of the research by colleagues, and analysis of taped interviews. A researcher with several years of experience of home care with stroke survivors or one who has volunteered as a fitness coach for a senior’s center might have strong biases about the nature of leisure based on his or her experiences. Another experience that might influence the ethnographic process is a researcher with a close family member who has successfully or perhaps unsuccessfully developed leisure activities after a stroke.
Limits of Ethnographic Research

A discussion of the limitations of a research approach is difficult because research strategies are based on philosophical beliefs about the nature of humankind and about the generation of knowledge. Often, the strengths of one approach are the weaknesses of another and vice versa. For example, Ottenbacher (1984) described one of the weaknesses of clinical trials as a lack of in-depth data, which is one of the strengths of the ethnographic approach. Elsewhere, the first author described one of the limitations of ethnographic research as difficulty in replicating the results, which is one of the strengths of a clinical trial (Krefting, 1989b). Further complicating the issue is the fact that many researchers have identified different criteria for rigor or trustworthiness for different philosophical approaches to research. For example, Agar (1986), Lincoln and Guba (1985), and Sandelowski (1986) argued that the rigor of ethnography is best assessed by criteria other than reliability and validity, such as credibility, transferability, and confirmability.

With the complexity of the issue in mind, many difficulties with ethnographic research must be acknowledged. Ethnographic research is often faulted on sample size and selection. Because samples are selected specifically for the question at hand and are not strictly representative, generalizability is often cited as a limitation. If an ethnographic study is based on the experiences of 10 people who have suffered a stroke, for example, the question might be asked, "To whom can the results be applied?" Moreover, detailed data are collected for a small number of informants, usually below the 30-subject rule of thumb used in research. Related is the issue of replication. Would another researcher investigating leisure among survivors of stroke who interviewed different persons and had different participant observation experiences arrive at similar conclusions? A pragmatic limitation of ethnographic study is that it is time-consuming in terms of data collection and analysis, which can be particularly problematic if funding is an issue. An ethnographic approach to leisure among persons with stroke might involve a minimum of 30 interviews and 15 participant-observation periods. Lack of standardization of data analysis and interpretation is another limitation. Although several strategies are available that address this problem, for example, audit trails, member checks, and code–recode procedures, qualitative researchers often react strongly against the flexibility of design, the cyclical nature of data analysis, and the subjective influence of the researcher on the analysis and interpretation. This perceived lack of objectivity is seen as lacking in scientific rigor, not as the strength of another approach to science.

Fortunately, the potential of the ethnographic research approach is being recognized in the field of occupational therapy, as evidenced by the March 1991 issue of AJOT, which is dedicated to qualitative research; the establishment of a Qualitative Research Interest Group that meets annually at the AOTA conference; and the funding of qualitative research projects by the American Occupational Therapy Foundation.

Ethnographic Examples of Persons With Disabilities

The reading of ethnographic research reports is one of the best ways in which one can come to understand ethnography. In addition to the published papers mentioned here, the literature includes a number of fine ethnographic accounts of the lives of persons with disabilities. Provided below is a selection of such ethnographies, which represent the scope of ethnographic work in the area of disabilities.

Several researchers have focused on persons with chronic mental illness who are living in the community. In these studies, the researchers have participated in the community of persons with mental illness and have based their conclusions on personal experience, intensive interviews, and participant observation. Estoff's (1981) book entitled Making It Crazy is an excellent example. She provided invaluable insight into the world of persons with chronic mental illness living in the community, based on her 2-year experience in that subculture. Her account is remarkable because of her ability to portray the world of this population in a manner that is accessible to both laypersons and professionals. Similarly, Reynolds and Farberow (1977) used a participant–observer approach to examine the experiences of patients with mental illness in an aftercare situation. An example of longitudinal ethnographic work is found in Edgerton's (1967, 1984) work with persons with developmental delay. Edgerton, a cultural anthropologist, focused on such persons' adaptive skills.

A number of studies of physical disability have involved qualitative research strategies. Notable is the work of Schneider and Conrad (1983) on the experience of epilepsy. Their book is the result of 80 in-depth interviews covering such areas as noncompliance, relations with physicians, and stigma. Kaufert and Kaufert (1984) used a similar method to study the experiences of long-term polio patients in Canada. Locker's (1983) study of 24 people suffering from severe rheumatoid arthritis discussed perceptions of activities of daily living, work and income, therapeutic intervention, social relationships, and family life. Goldin's (1984) 2-year study based on participant observation of a consumer advocacy group of blind people considered the cultural redefinition of blind persons and the politics of advocacy groups. Gubrium and Buckholdt (1982) conducted extensive participant observation in a rehabilitation ward, producing what might be called an exposé on the care of persons with disabilities. Roth and Eddy (1967) also used participant observation in their investigation of a long-term-care re-
habilitation institution for persons who were termed unwanted. Such descriptions contribute a rich and all-encompassing picture of the rehabilitation process.

Ethnographic approaches have long been accepted in the field of gerontology. One of the most notable contributions was made by Myerhoff (1978), who studied elderly Jewish Americans in Venice Beach, California. Gubrium (1975) used participant observation in learning about the institutionalization of elderly persons in the landmark book, Living and Dying at Murray Manor. Becker’s (1980) Growing Old in Silence is an applied anthropological study based on interviews with elderly deaf persons.

Conclusion

We have attempted in this paper to describe how an ethnographic approach might be applied to the understanding of leisure activities among persons who have survived a stroke. The idea of juxtaposing two research approaches to the same occupational therapy research question is intended to help therapists understand the range of research approaches that are available and to illustrate a variety of ethnographic strategies.

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