HIV Mental Health for the 21st Century

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Qualitative evaluation is a much underused and underappreciated tool that can help mental health professionals answer questions that quantitative techniques cannot address. Questions that qualitative techniques can answer include these: Why do adolescents engage in behaviors that put them at risk for HIV infection? What are the psychosocial concerns of women who live with injection drug users?

With the answers to these questions, one can create relevant and specific intervention programs. Then, when the programs are operating, qualitative techniques can help determine if they are meeting their goals.

Government agencies and foundations appreciate needs assessments as bases for program development. And these funding sources require evaluations for most programs. Qualitative methods are especially useful for exploring new topics, replicating work with new populations, and developing hypotheses. Moreover, evaluation studies can examine:

- Why and how programs work. This information is important to agencies that fund programs, to program planners, and to administrators, who may want to improve an existing program or recreate an existing program in another setting.
- Client issues and themes, especially in populations that are unfamiliar to providers or scarcely researched.
• How to make surveys relevant and in the natural vocabulary of respondents.
• Rich and deep details about causal relationships, beyond the statistical information provided by quantitative work.

Quantitative approaches, which use numeric assessments such as scores from assessment instruments and which are described in the previous chapter, are inadequate to explore these and similar questions.

Qualitative studies can help researchers explore the essence of experience in its natural setting. Because an experimental context is not imposed, qualitative work preserves the real world setting. And the resulting well-told story, with rich, well-grounded details, can have a greater impact than pages of statistical results.

Some people mistakenly believe that qualitative study is restricted to descriptive work or to the preliminary phase in research or evaluation. In fact, sophisticated qualitative work goes beyond description and can effectively be used alone or in combination with quantitative methods to assist researchers with many crucial questions.

Although there were sharp disagreements in the past, today most evaluators and researchers acknowledge the value of qualitative evaluation when used appropriately. Like quantitative evaluation, qualitative evaluation requires expertise, the use of known and accepted theory and practice, and the ability to make the results meaningful to a larger audience, such as public policymakers.

Qualitative research is based on a very different paradigm from that of quantitative work. Its essence is a belief that there is not one single reality. Rather, the qualitatively based evaluator accepts that different individuals and different groups have different realities, based on their personal, idiosyncratic interpretations. Those interpretations are what is described as meaning, according to qualitative evaluators.

Qualitative evaluators try to understand the meaning of each person’s experience, which may be unique with respect to time, place, and personal history. By time we mean not necessarily the hour or day but rather a socially defined period, such as an era or epoch or, perhaps, an epidemic. A person who has sex in the age of HIV/AIDS, for example, lives in a different time than one who was sexually active in the 1950s. By place, we mean not a geographic location but a psychological space—"where the person is at psychologically." This psychological place can, of course, be affected by physical surroundings and geography. The person in the inner
city is affected differently by his or her geography than is a person in a wealthy suburb. Finally, the concept of personal history is something we all know intuitively. If someone has a history of having parents die in a hospital, then that person is likely to have specific feelings about being hospitalized.

The task of the qualitative evaluator is to capture the meaning of a situation or condition to a person or a specific group of persons. Qualitative methods of data collection and analysis, which have as their goal the exploration of an issue or experience in a natural setting as contrasted with an experimental condition, follow from these understandings.

There is no single agreed-upon way to do qualitative work, nor even a standard within each of the qualitative fields. Miles and Huberman (1994) provide a comprehensive approach that is easily readable, particularly for researchers trained in quantitative methods.

**Major Theoretical Frameworks**

Paradigms—understandings of how we do science—differ in qualitative and quantitative approaches, and within the qualitative approach. Our paradigms guide how we think about data and how we develop useful information from the data. The major frameworks that underlie most qualitative techniques are grounded theory (Glaser & Strauss, 1967) and phenomenology (Cohen & Omery, 1994).

**Grounded Theory**

Grounded theory developed from the symbolic interaction school (Blumer, 1969; Mead, 1934/1964), which understands everyday life as based on shared meanings. Through interactions with others, meanings are continuously modified, and behaviors derive meaning and can become appropriate in the person’s social group. An example of a shared meaning in the area of mental health is the experience of the stigma attached to severe mental illness and its consequences for the patient and family.

Looking for understanding of basic processes or meanings and how they relate to each other, the evaluator who uses grounded theory begins with few or no hypotheses. Then, by gathering information in several possible ways, the evaluator develops and tests hypotheses and refines “theory” in an ongoing process.

In this context, *theory* means an understanding of experiences of the
participants from their perspective. Data collection and analyses occur jointly in a “constant comparative” process, as analysis of the initial data collection provides some understanding, or preliminary hypothesis, that is to be tested in the next data collection and analysis step. Using this ongoing process, the evaluator continues to develop and refine the theory.

An application of grounded theory is Swanson’s (1993) study of her clients with herpes simplex. She began by reading the available literature and used her clinical experience as a public health nurse to plan her study. Then, using interviews, Swanson explored the meaning of this chronic infection in the lives of middle-class young people. While she had some knowledge of this disease and some professional experience with it, she developed her “theory,” or her understanding from the perspective of the patient, from the data collected and analyzed in her study. She found that the psychological consequences of herpes are enormous and had critical impact on patients’ adherence to treatment. These results served as the basis for a psychological intervention with herpes patients to help them regain their self-worth and to manage their disease.

**Phenomenology**

Work guided by the second major framework, phenomenology, also begins with no formal hypotheses. Phenomenologists generally believe that there is no one reality to discover, in contrast to quantitative researchers. The phenomenologist seeks to understand the deeper meanings in the clients’ statements and actions by reflecting on the data to infer meaning. What does it mean for a mother to have an HIV-infected child with uncontrollable diarrhea admitted to the pediatric ward, for example? What experience does this mother have with hospitals? Do all people who come to the hospital die? Did a neighborhood child recently die? Is she a bad mother if she cannot prevent her child from being sick? This approach of logical insight and heightened awareness (of the researcher) based on careful consideration of all information can bring to light the essence of the experience.

Because this approach uses a high level of inference, evaluations based on phenomenology have been criticized as more subjective than those based on grounded theory. Some say phenomenology is more an art than a science. This perception has limited funding by government agencies and private foundations, and hence this approach is used relatively less often.
Evaluation using this approach generally focuses on needs assessment or on the description of implementation of a service program, as contrasted with studies to demonstrate the effectiveness of a service program. See van Manen (1990) and Patton (1990) for further descriptions.

One researcher whose work in this area is especially compelling is Jan Morse, who, in the tradition of nursing, has studied the phenomena of enduring and suffering as well as comfort (Morse, Bottorff, & Hutchinson, 1995). As part of a larger program of study, Morse used information from interviews to identify stages in the process of coping with major personal loss. She and her colleagues found that initially the person may be just barely hanging on to reality, using all available mental energy just to “endure.” Later the person may be able to process the tragic event and work through the process of “suffering.” Understanding where a person is in coping is crucial to the nursing process.

By now it should be evident that qualitative evaluation can assist mental health providers in two areas. The first responds to the question, “What is the meaning of a specific experience to clients?” which leads to program development. The second area grows out of the question, “How does the program work?” The techniques described can be applied to various questions, including program evaluation. The chapter concludes with a discussion of concerns specific to program evaluation and some thoughts on combining qualitative and quantitative techniques.

**Qualitative Evaluation for Program Development**

Too often, when program administrators learn that funding is available for mental health services for HIV-infected persons, providers create service programs without much consultation with the community regarding what is actually needed. A better, and stronger, approach in competitive funding is to have a qualitative evaluator actually ask those with a stake in the situation (stakeholders) questions that can lead to development of a responsive program. Stakeholders typically include clients, program staff, local program administrators, and policy decision makers.

The evaluator, then, does a literature search to determine what others have reported about similar issues. Using this information, the evaluator plans to explore these issues with the community through the use of focus groups and interviews.
Focus Groups

Use of focus groups is a recently popular approach that provides insight into complex behaviors and that is useful in learning why people think or feel the way they do. Although there is not a single definition of focus groups, there is a general consensus that they use a semistructured format, are moderated by one or two leaders, are held in an informal session, and have the purpose of collecting information on a designated topic. Although group sessions may provide group members with useful information and some moral support, the intent of this data collection technique is information gathering. This section briefly describes the basics of the focus group technique. For additional information see Krueger (1994) and Carey (1994); for some advanced topics see Morgan (1993).

To prepare to run a focus group, researchers explore what is known about the designated topic and then formulate three or four general questions that provide the structure for the session. Group size varies with the experience of the group members and the nature of the topic. For people who are not used to being in groups, when the topic is very sensitive, when the group interaction is expected to require extra attention from the leaders, or when the leaders are inexperienced, four to six people are suggested—a smaller group than the usually recommended five to twelve.

The group leader guides the discussion and probes for depth and range of specific personal experiences and for inconsistencies in description. After a group member describes his or her experience in response to the leader's general question, another person will respond, providing a more-detailed story. This group interaction is what brings out the depth and richness of data. For topics that may elicit emotionally laden responses, the leader must constantly monitor the group for the level of comfort and intercede to prevent injury. For this type of session, it is important for the leader to have clinical expertise.

The research purpose of a focus group can range from an in-depth exploration of the experience of foster parents caring for a child with HIV to the identification of issues and natural vocabulary for the development of an instrument. The chemistry of the group will affect what people say, and the evaluator will need to consider this factor when analyzing the data. The group interaction both enhances the collection of rich data and may inhibit some participants' description (i.e., as they seek to fit in with the group) (Carey, 1994).
After focus groups are conducted, the evaluator may use the information gathered to further refine the questions asked and then revisit the groups to seek further depth and detail.

**Interviews**

There are many possible ways of structuring interviews. The evaluator may have well-defined questions, use a highly structured format for asking questions, and have specific instructions for asking follow-up questions. This approach permits the collection of quantitative data, similar to an oral version of a questionnaire.

In contrast, an open-ended approach may be appropriate for some purposes, such as when clients' concerns are not known. Broad topics with general instructions for follow-up questions permit a wider range of possible responses but are more time-consuming to analyze. An example of a broad topic is: What services are most useful in helping you cope with a positive HIV-test result?

The advantages and disadvantages of each approach to interviewing have been well discussed in the literature. The classic reference on interviewing is Kahn and Cannell (1957), and an informative discussion is provided in Pedhazur and Schmelkin (1991).

**Data Saturation**

Generally speaking, the process of conducting focus groups or interviews ends when "data saturation" occurs, that is, when additional interviews or focus group sessions yield no new information. Saturation refers to the richness and detail, not to the amount of data (Morse, 1995). Data saturation is actually more a conceptual goal than an actual occurrence.

Often the resources limit the amount of data collection. The evaluator should, however, feel comfortable with the data collected for the purpose of the study. It may be necessary to narrow the goals of the study, to focus on a narrower population, or on only one aspect of the experience.

**Data Analysis**

Qualitative approaches can be intuitively appealing and, deceptively, can appear easy. A clear and well-articulated plan of analysis is crucial to credibility and therefore to the usefulness of the results. Planning for analysis should be done before data are collected.
Qualitative data analysis is quite different from quantitative analysis, which analyzes the numbers obtained from different instruments and uses statistical methods to determine whether statistically significant differences have been found between groups. Qualitative analysis may use one of several different approaches to discover commonalities and variations in the data and try to understand the meanings.

One useful approach in analysis is the process of condensing, clustering, sorting, and linking data as described by Miles and Huberman (1994). Basically, the first step is developing categories in the data (condensing). The researcher then tries to discern one or more themes (clustering). The process of sorting helps the researchers determine who said what; for example, African Americans across focus groups may have responded one way to a question and Asians, another way. Linking data is the process of connecting themes to the responses across sites or groups.

The purpose of the first step in the analysis of data—called first-level coding—is to develop general categories. For example, reading through the transcripts of focus groups sessions, I would note concerns that may be similar to the planned questions that were asked in the session; often, however, other issues arise. For many evaluators, the initial categories are fairly concrete and factual. Next, in second-level coding, as I looked across these initial codes, I would look for broader themes such as distrust/trust of the medical system. I would then explore similarities and variations in relation to subgroups in the sample. Do clients follow medical advice better when they can be seen by medical personnel of the same ethnic group? Results would then be "recontextualized," which means that I would go back to the data to verify that the themes noted and their relation to appropriate subgroups were accurate. Identifying examples of themes and relationships may lead to further analysis.

Appropriate documenting of each step of the analysis process is necessary if the results are to have credibility. A reasonable person should reach the same conclusion as the evaluator. In a study of health care personnel who provide care in settings with a high risk for HIV transmission, for example, Duffy (1994) reviewed her analysis of interviews with a team of both qualitatively and quantitatively trained researchers. Each step in the analysis was examined for logical consistence and appropriateness.
Evaluation of Existing Programs

Evaluability

Not every program can, or should, be evaluated. Program developers, and those writing grant applications, can create significantly stronger — and more fundable — programs by designing programs that combine services with the requirements of evaluation. Before evaluation can occur, one must have a clear understanding of the program's target population and its purpose. Only then can evaluation determine if the program's goals are being met for the specific population.

Evaluation takes staff time and costs money. If an evaluation is conducted, the practical limits on the usefulness of the evaluation results should be known. If the goal of the program is a particular long-term effect of service, for example, other factors may also affect clients and therefore restrict the cause-and-effect statements possible regarding the program impact. Also, one should know if the program will actually be modified based on the evaluation results.

To be "evaluable," a program must have common goals and a common description. This is important in designing a new program, and particularly important for evaluating an existing program. Because clients, staff, managers, policymakers, and evaluators probably have different perspectives and values, developing a common definition of the program is the first step. This can be done through focus groups and interviews. If program planners and staff have difficulty in identifying goals and program effects (summative evaluation) or the important processes in delivering the program (formative evaluation), the evaluator may ask how they would know if their program worked well or have them describe how an ideal program would work (O'Sullivan & O'Sullivan, 1994).

Wholey (1994) describes criteria to consider in determining whether to evaluate a program. They are the existence of well-defined program goals and information needs, plausible program goals, availability of program information, and agreement on the uses of evaluation results. Programs that cannot meet these criteria or that cannot be modified to do so probably should not use limited resources to evaluate.

After performing an evaluability assessment, the researcher can make a decision on the relative importance of evaluation for the program in question. With adequate resources, the needed expertise can be obtained or personnel trained. Evaluation techniques are usually the enlightened
application of good research methods. Computer software is now available to make coding and analysis much easier, permitting a more thorough examination. See Weitzman and Miles (1995) for a review of software.

When a new program is designed to be evaluable, or an ongoing program is found through an assessment to be evaluable, administrators need to consider resources, sampling, and design issues.

**Resources**

Adequate resources—people, expertise, money, equipment, data systems—must be available and the time frame for the evaluation must be realistic. Without a requirement for evaluation or recognition of its importance, the usually scarce resources will be spent on services and not on evaluation.

**Sampling**

An important life experience is often perceived differently by various groups. An evaluator will, therefore, have to consider important characteristics when creating the sample group. Segmenting the target population in meaningful ways and purposely sampling within relevant categories will enhance the likelihood of collecting an appropriate range of data. If the effects of the program are expected to vary for men and women and for ethnic minorities, for example, it will be useful to plan to have adequate numbers of research participants representing each of these groups.

In the final report, the evaluator will likely mention how the sample was recruited. This will assist readers in understanding how the people actually recruited represent the population that is the target of the study. This information is necessary in interpreting how well the study results can apply to people beyond the sample (external validity). Miles and Huberman (1994) provide an excellent discussion of sampling and offer sound advice for the novice evaluator.

**Design**

Statements of program effects are limited by the design of the evaluation. To say confidently that a service program leads to client improvements and that results are not influenced by nonprogrammatic factors
such as employment or peer supports, the design of the evaluation must be rigorous.

This is the same concern that surfaced with regard to confounds in the previous chapter. One must be able to determine that the program made the difference or to what extent it contributed to the outcome. As a result, qualitative evaluators seek to understand the program in its natural context—what is actually happening in the world of the client and what other events and treatments might have had an effect on the program outcomes. For all types of studies, the focus is on ruling out other potentially relevant causes—"rival hypotheses"—not ruling out all possible causes.

Due to ethical considerations and practical logistics, most service programs are not able to use rigorous experimental conditions with random assignment of subjects. Evaluation therefore requires that the experimental design be modified. Most qualitative evaluations are not true experiments with control groups; consequently, cause-and-effect statements will be arrived at by comparing program results with those from a comparable group.

Descriptions can provide useful information about service effects. In a new program that provides mental health services to persons with HIV/AIDS, for example, quality of life and level of stress may be assessed at entry to service and six months after services have been provided. By describing the program, the clients, the barriers to care, and the costs of care, such a program evaluation can provide useful information for program planners in terms of feasibility and acceptability of the new service delivery model. This type of evaluation is not intended to provide cause-and-effect statements; it is preliminary to further evaluation of effectiveness.

**Combining Qualitative and Quantitative Approaches**

Many studies use a combination of qualitative and quantitative approaches. The not uncommon practice of adding a few quotes to the statistical results does not really take advantage of the potential of qualitative data. Planning for the best use of each approach should consider the purposes and strengths of each, and any combination should take advantage of their complementary strengths. The purposes of combination include:

1. Expansion: Going beyond the limitations of each method. An example of expansion is O’Brien’s (1993) use of qualitative technique in the develop-
ment of a questionnaire in HIV/AIDS research. She used focus groups to explore issues and problems in the lives of adult males. By so doing, she identified major areas that then became the basis of the questionnaire items. Natural vocabulary for questionnaire phrasing was also obtained.

2. Explanation: Understanding data and results. A common approach uses quantitative data to inform the development of a qualitative study. Epidemiological data regarding substance abuse, for example, can be used to target populations for a qualitative study of coping with stresses of living with HIV infection. On the other hand, focus groups or interviews may help in understanding quantitative results that are unexpected and not readily interpretable. This approach can provide the evaluator with new insights and avenues to explore.

3. Reinforcement: Enhancing credibility. The process of reinforcement increases believability when data from two sources, using different collection methods, produce the same results. When questionnaire data may be regarded as underreporting the occurrence of a phenomenon, such as substance abuse, or when the generalizability of focus group data is limited by logistic issues, the concurrence of data allows the evaluator to weigh the results more effectively.

In work with HIV patients in the military, Carey and Smith (1992) used qualitative data to improve the overall program of research. Input from a protocol adviser who is a former military person and who is HIV-positive, a patient advisory panel, and focus groups was used to improve the research program. The researchers began by focusing on the validity of the psychosocial instruments, which had not previously been used with a military population. It was quickly apparent that the validity of the research process was in question. The logistics of scheduling appointments for medical and research purposes and the burden of the lengthy questionnaires led the researchers to reconsider the research experience for the participants and to revise the protocol. They reduced the number of questionnaires and coordinated the scheduling for the convenience of the participants.

Case Study and Ethnography

Two approaches that combine qualitative and quantitative methods are case study and ethnography. Both approaches can be helpful and may, in selected cases, be useful in outcomes evaluation.

Although often thought of as solely a qualitative methodology, the case study approach actually uses all relevant information. Without using many
cases (and in contrast to a typical quantitative approach, which has enough subjects to permit the appropriate statistical analysis), a case study examines one unit, such as one community. Here "case study" does not mean the discussion of a single client or patient, the term *case* refers to that unit of the study's focus, which is generally at an aggregate level. Using multiple cases can increase confidence in the results, and this technique can be used to explore a topic more broadly (e.g., examining a program's effects on different ethnic populations).

The second approach that combines qualitative and quantitative approaches is ethnography. Focusing on structure, ritual, or symbols, the researcher uses all relevant data to study a population from the perspective of its culture. The drug culture of an inner city, for example, might best be studied with an ethnographic approach.

**Conclusion**

With the increasing emphasis on program development and evaluation, qualitative methods will have a significant role in assessing HIV mental health programs. Personnel who are comfortable with qualitative evaluation and understand its potential usefulness will more likely receive funding, create and administer quality programs, and take a leadership position in the next century.

**REFERENCES**


