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How Qualitative Methods Contribute to Understanding Combination Antiretroviral Therapy Adherence

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Summary

Strict adherence to medication regimens is generally required to obtain optimal response to combination antiretroviral therapy (ART). Yet, we have made limited progress in developing strategies to decrease the prevalence of nonadherence. As we work to understand adherence in developed countries, the introduction of ART in resource-poor settings raises novel challenges. Qualitative research is a scientific approach that uses methods such as observation, interviews, and verbal interactions to gather rich in-depth information about how something is experienced. It seeks to understand the beliefs, values, and processes underlying behavioral patterns. Qualitative methods provide powerful tools for understanding adherence. Culture-specific influences, medication beliefs, access, stigma, reasons for nonadherence, patterns of medication taking, and intervention fidelity and measurement development are areas ripe for qualitative inquiry. A disregard for the social and cultural context of adherence or the imposition of adherence models inconsistent with local values and practices is likely to produce irrelevant or ineffective interventions. Qualitative methods remain underused in adherence research. We review appropriate qualitative methods for and provide an overview of the qualitative research on ART nonadherence. We discuss the rationales for using qualitative methods, present 2 case examples illustrating their use, and discuss possible institutional barriers to their acceptance.

Keywords

adherence; antiretroviral therapy; international research; intervention research; qualitative research

Among individuals living with HIV/AIDS, strict adherence to medications is generally required to obtain optimal response to antiretroviral therapy (ART). Even relatively brief and minor lapses in adherence have been shown to compromise the efficacy of HIV treatment, leading to preventable morbidity and mortality.[1,2] In response, the National

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Institutes of Health (NIH) have made a commitment to understand and promote ART adherence.

The extensive efforts of the HIV research community have advanced the understanding of measurement of adherence and its association with HIV-1 RNA viral load and other health outcomes. Overall, however, we have made limited progress to date in developing strategies to decrease the prevalence rate of nonadherence.[3] Further, we have been unable to identify correlates of adherence in a manner that allows for the reliable prediction of nonadherence. A comprehensive theory of adherence also is lacking. As we work to understand adherence in developed countries, the introduction of combination ART in resource-poor settings throughout the developing world raises novel challenges. New tools are needed to meet this need.

Qualitative research is a scientific approach that uses methods such as observation and interviews to gather rich in-depth information about human experience. Such research seeks to understand the mechanisms that generate behavioral patterns. The methods of qualitative research provide powerful tools to increase our understanding of combination ART adherence. Areas ripe for qualitative inquiry include culture-specific influences, patients' beliefs about their medications, access, stigma, reasons for nonadherence, patterns of medication taking, and intervention fidelity and measurement development. Qualitative methods are essential for understanding the values, motives, beliefs, and relations that are important in adherence to ART.[4] A disregard for the social and cultural context of adherence or the imposition of adherence models that are inconsistent with local values and practices is likely to produce irrelevant or ineffective interventions. To date, qualitative research methods remain underused.

This call for a greater role of qualitative research is consistent with NIH recommendations for the use of qualitative research to determine the now well-documented social and cultural dimensions influencing health.[5] Moreover, qualitative research has proved useful in other areas of HIV behavioral research. For example, the methods made significant contributions to reducing HIV transmission by documenting the relation between sexual orientation and sexual practices.[6,7] Observations by ethnographers about the frequency, conditions, and physical and social milieus of sharing and pooling needles have been essential in understanding the epidemiology of AIDS and in designing effective interven-tions.[8–12] More widely, qualitative studies contributed substantially to our understanding of treatment adherence for other chronic illnesses, including diabetes,[13,14] smoking,[15] and hypertension,[16,17] as well as in adaptive device use[18] and oral rehydration therapy (ORT).[19]

In the present article, we review qualitative methods and provide an overview of the qualitative research on ART nonadherence. To illustrate the potential use of qualitative methods in ART adherence research, we discuss the rationale for their use and describe 2 case examples. We conclude by suggesting several areas in which qualitative research could be better used to advance knowledge in this field. This article focuses on the use of qualitative methods in ART adherence research specifically and is not meant to be an introduction to or detailed discussion of qualitative methods in general. For that, we refer the reader to other excellent sources.[20–27]

WHAT ARE QUALITATIVE METHODS?

Qualitative methods are designed to discover and describe the participants', or "insider," perceptions, views, beliefs, and experiences in their own terms in contrast to using outside researchers' definitions and categories. There are 4 main types of qualitative methods: interviews, observation, archival research, and a combination of those known as rapid ethnographic assessment (Table 1). Within each of these broad categories, there is a range of methods.

Qualitative Interviews

Qualitative interview methods include individual and group approaches to data collection. They feature in-depth and extended discussions guided by an interviewer. They vary in the degree of structure involved. On one end of the continuum are semistructured interviews using predefined questions that allow open-ended responses. Open-ended interviews are less structured and use a list of discussion topics to cover in each interview. Least structured are the informal interviews. These are casual discussions with research participants that typically address issues emerging in the conduct of ethnography and are used to clarify aspects of the research context or to provide more in-depth understanding of topics. They are a systematic way to explore an observed behavior pattern and may augment data gathered by observation.[28,29]

The flexibility of these methods is illustrated by examining "side talk" about the measures. This type of useful qualitative data arises not from interview questions but from queries that interviewees ask to seek clarification, express puzzlement, or challenge the validity or sensitivity of a question. These comments can be noted and used for follow-up probes or as the basis for a more systematic review of an interview item.

Focus groups involve 6 to 12 people in 1- to 2-hour discussions exploring topics led by a facilitator. Focus groups were originally developed in market research.[30] They are designed to obtain the consensus of a group selected to represent a specific condition or identity (eg, homeless HIV-positive veterans). They can be used to obtain early impressions of a target population, assist in the development of interview protocols, facilitate the assessment of patient education materials, learn about behavior under different treatment regimens, and validate and elaborate information gathered by other means.[4] They can also be used to elicit reactions to outreach programs or to inform product design. Focus group data do not provide causal explanations; rather, the exchanges among group members bring out and explain the lay folk models for topics such as adherence challenges.[31] Repeat focus groups, like repeat interviews, can be used to explore changes over time.

Observation

The uses of observation as a qualitative method range from nonparticipant observation to the integration of the researcher into the research setting in ethnography.

Nonparticipant observation is the least intrusive type of observation methodology. This can take several forms. A researcher can shadow a research subject such as a health care professional or community service worker through a daily routine. This provides a context

for interview data and allows the researcher to get a feel for a setting. This type of observation is also used in studies of clinician-patient communication, in which a trained observer studies the form, proxemics, and content of an interaction. In some designs, the researcher does not participate in the research setting but "observes" communication on a videotape.

Participant observation provides an immediate and intimate understanding of a situation through the simple fact of "being there" and through participating in the daily interactions of a setting or organization. This approach is used in the construction of case studies that involve several visits to a field site but lack the prolonged interaction and personal involvement characteristic of ethnography.[32] In HIV research, observations by ethnographers about the frequency, conditions, and physical and social milieus of needle sharing and the pooling of needles have been essential in understanding the epidemiology of HIV[4] and in designing effective interventions.[8]

Archival Research

Archival data have not been created expressly for the purposes of the research project but may provide additional windows into understanding the research topic and bear on the interpretation of findings. Archival sources include data with limited access such as clinic structure and organization and data in the public domain like medication advertisements or patient education material, pharmacy inserts, documents relating to health care policy, and histories of the HIVepidemic and of treatment development, which can be the focus of qualitative research itself or can contribute to a design examining various aspects of adherence. Also included in this category are sources in the public domain illustrating popular cultural understanding of HIV and of combination ART such as television shows, plays, artwork, and advertisements for ART medications. These sources depict how the popular culture understands the epidemic, those with the disease, and its treatment and may provide insight into the sources of stigma, conspiracy theories, and the lived experience of people with the disease.

In qualitative research on adherence, patient medical histories documented in the text form of a medical record can be considered a type of archival data. Although not the topic of the research, data located in a medical record such as the clinical markers of adherence, CD4 cell count, viral load, and genotypic resistance can provide a source of triangulation for patient self-reports of adherence, hence enhancing the validity of the qualitative findings.

Ethnography and Rapid Ethnographic Assessment

Ethnography is a qualitative method that involves regular extended participation in a setting under study, and it may use several qualitative methods to provide a rich full description of a social setting, event, or phenomenon. Through participation in the setting and systematic observations, along with formal and informal interviews, the researcher gains an intimate and detailed understanding of a particular set of questions. Research on clinic culture and operation; physician and patient relationships; informal settings for health care delivery; and individual and familial experience of disease, illness, and treatment are topics that lend

themselves well to ethnography. Adherence research to date has made little use of ethnographic methodology.

One specialized method of relevance to health research is rapid ethnographic assessment. Also known as “quick ethnography”[33] or “rapid assessment process,”[34] this method combines the several techniques into a brief and focused research design. It is used widely in HIV prevention research.[35–37] Depending on access to infrastructure resources, a rapid ethnographic assessment can be conducted in a few weeks. It is valuable for obtaining an initial understanding of a situation and in resource-poor settings.

In rapid ethnographic assessment, one first reviews archival data such as central government policy reports, local government reports, health statistics, agency reports, hospital records, and local newspapers to determine the scope of the research topic, collects relevant statistics defining the problem, and identifies local stakeholders. Through this process, key informants should be identified. If the research is conducted in non-Western countries, the following steps must involve researchers fluent in the local language and local researchers familiar with the setting and research problem.

Key informants are people in the community with specialized knowledge about a topic or practice. In the case of adherence, key informants may include local physicians, nurses, pharmacists, and social workers or outreach workers in addition to HIV-positive persons. Key informants also include non-Western healers and people who dispense medication in informal settings (eg, market stalls, street networks) and local leaders such as the clergy, elected officials, and constabulary. Community opinion leaders or people in a position to influence attitudes such as stigma toward people with HIV should be interviewed. Key informant interviews are used to obtain an insider’s view of the topic of the research so as to construct culturally and locally appropriate items for inclusion in a focus group, to identify the type of individuals and possible candidates to include in a focus group, to identify community settings for observation and ethnographic mapping, and to learn about features of the research topic that a researcher may not have considered.

Focus groups are conducted to build and refine insights from key informant interviews. These serve to confirm or qualify perceptions and understanding emerging from individual informant interviews. Focus groups can further refine the data collection scheme by evaluating sites for observation suggested by key informants. If a survey is planned, the focus group can provide feedback on the survey items themselves.

Observations are a nonparticipatory form of data collection in which the researcher observes key locations identified in the previous interviews, notes key players in those settings, and looks at types of relations and barriers or facilitators to the topic of research. In the case of adherence research, observations might include a neighborhood clinic or informal source for medication that has been identified by key informants or focus group members. For example, in some African countries, black market ART medications are available in market stalls and dispensed by people with no formal medical training (Jessica Price, PhD, personal communication, 2006).

Ethnographic mapping builds a map that depicts the actual concrete community or region and shows the distribution and relations among resources, people, and patterns of behavior in the target community. It involves a combination of observations and informal interviews. In this process, information gained from the key informant interviews and focus group interviews and from observations is confirmed through interviews in the research setting.

For example, a study about combination ART adherence in a non-Western city might focus on a neighborhood clinic and the interactions of health care professionals and patients. Ethnographic mapping would delineate the roles of the different providers and the types of interactions they have with patients, would confirm those observations in interviews with these people, and would then build on basic observations and confirmatory interviews to pose more in-depth questions concerning the research topic. This method is useful in identifying nonstandard medication distribution networks, their members, and the sources of medication.

ADHERENCE RESEARCH QUESTIONS SUITED TO QUALITATIVE METHODS

At least 4 types of research questions are suited for qualitative methods: (1) discovery and characterization of relevant factors to measure, (2) characterization of phenomena not well captured with quantitative methods, (3) exploration of unfamiliar social and cultural issues such as topics relevant to cross-cultural and minority populations, and (4) evaluation of the validity of findings.[38] We examine these questions, explore their particular framing in ART adherence research, and provide an example of the use of qualitative methods to address each question with respect to ART adherence.

Discovery and Characterization of the Nature and Salience of Factors Relevant to Adherence

Qualitative methods serve to identify and describe the appropriate basic units for analysis and characterize key factors and measurement strategies. Qualitative methods are used where there is a paucity of facts and data on the exact factors, the basic units of analyses, and processes. Such information is a critical first step needed to design the parameters of a study. For example, qualitative methods can contribute information on the salient contexts of and dimensions involved in a patient's adherence practices, including decision making about pill taking and the personal and social settings, values, and beliefs associated with trying to adhere to medical advice.

Notably, only some of these concepts can be converted to structured measures by further development. Other constructs, because of the nature of the phenomena they capture, may not be suited to standardization and always require systematic but open-ended approaches.

Appropriate Qualitative Methods—To identify factors germane to adherence practices, 2 qualitative methods are especially appropriate: ethnography and open-ended interview discussions.

Ethnography, a traditional tool, provides a systematic description of a social setting from the inside perspective of the participants in their own language rather than in the observer's language. Typically, the researcher collects data while participating in the daily public and personal lives of participants. Ethnographies provide an extensive detailed understanding but can require considerable time and effort. Open-ended interviews are a focused method similar to an informal conversation that is guided along predefined topics and allows for flexibility in follow-up on new topics as they emerge. These have a narrower focus and, unlike ethnographies, may not capture all relevant ideas and values manifest in group settings and from observation of patterns of actual behavior. Their strength is that they allow us to document the meanings and intentions that guide a person's choices of behavior and self-evaluations.

Example—To improve their ability to measure adherence for a trial of a planned intervention, Ryan and Wagner[39] conducted a qualitative study to understand patients' own categories and units of adherence experience. They focused on "episodic adherence," which they differentiated from "global adherence," the more common measurement focus in adherence research. By studying episodic adherence, the authors aimed to capture the actual experiences of each day's adherence events in which people adhere sometimes and sometimes do not. Global adherence instruments are ineffective for understanding individual episodes of nonadherence, particularly when it is intermittent. Neither do global measures assess well the role of daily life events in adherence practice because they only gauge the overall likelihood of a person taking his or her medication in a timely manner. They cannot capture the reasoning behind the taking or not taking of individual doses. In contrast, this exploratory study contributed insights into contextual factors that shape an individual's daily adherence choices, which notably led to episodic nonadherence.

Methods Used—Open-ended qualitative interviews were conducted with a sample of 27 consecutive patients enrolled in an ongoing adherence trial, who were selected to include persons who had missed 1 or more doses of antiretroviral medication during the past 2 days (based on medication event monitoring system [MEMS] cap data).[39] The researchers collected a 24-hour recall for the day when the participant missed a dose and conducted open-ended interviews to assess patient explanations for pill-taking behavior and life activities and experiences on the preceding 2 days.

Findings—Analyses reveal salient daily events and decisions that were masked by the overall global measures. They indicated that the ability to integrate pill-taking adherence into self-constructed daily routines and adjust to changes was associated with a high degree of adherence. Some patients were confused about when to consider a dose as missed; substance use (drugs and alcohol) disrupted routines, and this in itself contributed to nonadherence.

Significance—Qualitative methods were able to identify subtle shifts in adherence practice that were undetectable with global assessment instruments. Understanding these shifts in behavior contributed to the formulation of the construct "routinization," which is further examined in a quantitative research design.

Characterization of Phenomena Not Well Described by Existing Quantitative Methods

A variety of vital phenomena are not adequately captured by standardized measures but can be assessed by qualitative methods. Examples of data available through qualitative methods include histories (individual and group), information embodied in storied or narrative forms of reasoning, symbolic forms, and dynamic processes such as decision making. In the case of adherence, knowledge best obtained by qualitative methods includes the patients' experiences of decision making regarding medication taking, patients' thoughts regarding how disease created physical disability and life challenges test their cultural values and beliefs, or patient models about ART efficacy. Patients' beliefs about the causes of illness and their perceptions of the services available to treat them significantly influence whether, when, and where they seek care.[40]

Appropriate Qualitative Methods—To elicit these kinds of person-specific individual level data, the appropriate qualitative methods include case study approaches using semistructured and in-depth interviews, narratives, and personal diaries.

Example—Roberts and Mann[41] sought to understand how patients differentiated between intentional and unintentional non-adherence. Intentional nonadherence occurs by patients' conscious choice; that is, patients have full knowledge of how to take their pills as prescribed but choose to do otherwise. Unintentional nonadherence occurs because of a lack of knowledge about the pill regimen or outside conditions such as financial barriers preventing patients from taking the pills properly.

Methods Used—The authors used a narrative approach facilitated by patient diaries. The diary method allowed participants to record their experiences and feelings about their medications in their own words. This method provided an in-depth record of participants' lives, richly illustrated the conundrums faced when considering how to adhere or not to adhere, and shed light on the decision-making processes that patients went through regarding taking their ART.

Findings—Roberts and Mann's analysis[41] showed that each person's decision to nonadhere intentionally is rational and complex rather than irrational. The decision was made after careful evaluation of not just health issues but the potential social consequences and implications for self-image and life values. Patients' decisions about adhering are fluid and rarely final; that is, patients continually review whether and when they should adhere. A decision to stop the medicines when on vacation makes less sense when returning to regular life. These decisions, and the internal renegotiation that accompanied them, could be influenced by particular life circumstances, spiritual and/or religious beliefs, physical health status (ie, whether the medicines are causing side effects), and social relationships. For example, for one woman, the quality of the interaction with her physician was especially instrumental in changing her adherence routine.

Significance—Qualitative methods captured the personalized individual reasoning process that people engage in when adhering to medication. These findings provide insight into

individual practice, decision-making processes, and the ongoing challenges of adhering to ART over time.

Exploration of Unfamiliar Social Settings and Cultural and Ethnic Contexts and Identification of Issues Salient to Persons in Those Settings

Culture is defined for adherence research as those shared values, norms, and standards of community sentiment that shape and give meaning to actions and structure how people interpret behaviors and experiences of being HIV-seropositive and taking ART. Thus, culture is empiric and can be reliably documented. Researchers in a community should not, however, view culture as a single coherent system. Rather, culture is best defined for purposes of research as the confluence of multiple different local family and community traditions and ethnic/racial heritages coming together in a particular historical time and place. Culture is not viewed simplistically only a source of solace and positive values but is also conceptualized as the source of deeply felt distress rooted in, for example, negative social stereotypes, stigma, or unachievable ideals and expectations.[42] The concept of culture is important for adherence research. It highlights the need to assess the experience of being HIV-seropositive and the cultural acceptability of taking ART by reference to particular local social and belief systems. These systems include folk medical beliefs about ART as a treatment for HIV. Cultural beliefs about HIV, ART, and research in general are significant factors in determining the validity of research constructs and the acceptability of interventions and methods and technologies of research.

Appropriate Qualitative Methods—Several qualitative methods are suited to assess cultural factors that may influence adherence. First, ethnography can be used to study the role of culture in ART adherence. For example, the ethnographic description of HIV clinics is an effective technique for determining the system of care for HIV-seropositive individuals in non-Western settings and for documenting the lived experience of people with HIVadhering to ART. Second, open-ended interviews can be used to determine the influence of culture on the research process in question. For example, because local cultural beliefs frame the key constructs involved in the understanding of illness, health, and treatment, researchers should determine the culturally appropriate phrasing of constructs in the study of ART adherence. To ensure that these constructs are valid and that they are presented in a meaningful manner to research participants, it is necessary to engage in a process of initial translation and back-translation[43] when working with groups that do not share the same idiomatic language as the researchers. These considerations extend to the conduct of the research itself. The acceptability of written and verbal response tasks and of the technology used for adherence measurement, such as an electronic monitoring device (EMD),[44] should be ascertained rather than assumed (Ira Wilson, MD, personal communication, 2006). Open-ended interviews in which the research participants are allowed to introduce and discuss culturally relevant constructs for describing their experience are valuable for these tasks. Semi-structured interviews have limited value in the initial stages of cross-cultural research because they require significant expertise in the local language and culture to be valid. Especially when ethnic minorities are examined (in the United States or in multiethnic countries abroad), substantial development is required to provide culturally relevant assessments and measures.

Example—Rowe and colleagues[45] sought to understand the barriers and facilitators for adherence to tuberculosis preventive therapy (TBPT) for HIV-seropositive people in South Africa. They were particularly interested in learning how to foster and maintain adherence in resource-poor settings. The authors point out that although much has been learned from the experiences of industrialized countries about the introduction, monitoring, and potential adverse side effects of treatment regimens, in resource-poor settings, understanding the perspectives of local communities and cultures is critical for understanding their specific adherence issues.

Methods Used—Because little was known about the relation between Western and traditional medical care for HIV, the authors chose to administer open-ended in-depth interviews to explore patient and health care workers' perspectives on adherence. Patients were interviewed in the clinic or their home. Health care workers were interviewed in the clinic.

Findings—The study found that lack of finances for transportation to a clinic was a key barrier to medication taking. Lack of food security (by which the authors meant regular meals) was also a barrier for poor patients who believed they had to take their medication with food. For some women and adolescents, absence of autonomy within the family (hence, lack of the ability to make their own decisions about medical care) posed a barrier to clinic attendance. Fear of exposing their HIV status was also a barrier to clinic attendance in some cases; conversely, the fact that the HIV clinic was separate from the main hospital was reassuring for others. Importantly, many people believed that HIV could not be cured, drawing this conclusion from prevalent HIV prevention campaign literature proclaiming "HIV kills." Many thought only traditional medicine could cure HIV and that the 2 types of treatment could not be mixed.

Significance—Findings from this study contributed to the development of effective adherence programs in South Africa. In particular, it emphasized the significance of the role of a supportive and educational clinic environment in promoting adherence. Importantly, these findings point to the need to forge an effective link between Western and traditional healers so as to develop an effective treatment program. Finally, to address the problem of financial barriers, the clinic instituted a system of financial incentives that demonstrably improved adherence.

Validation of Findings

Qualitative methods can be used at the end of a study to help evaluate the validity of findings or the fidelity of intervention procedures.[44,46,47] In a 2002 review of randomized controlled trials, the *Journal of the American Medical Association*[48] stated that qualitative research should accompany randomized controlled trials to determine whether the intervention delivered matched the intent specified in the research design. Post hoc qualitative interviews can be used to determine (1) if the procedures followed by those administering the intervention were faithful to the procedures specified in the research design, (2) if the understanding and experience of the intervention participants matched the intent of the intervention's designers, and (3) if the intervention had any unintended

effects.[44] Qualitative methods can thus assess if the intent of the intervention was achieved. Qualitative methods are appropriate in the assessment of interventions for which the domains and processes are underspecified. The results can be used to develop standardized measures for assessing subsequent interventions.

Appropriate Qualitative Methods—To assess the validity of intervention results, qualitative methods ranging from exploratory descriptive studies to more structured free listing or process analysis can be used.[46,47] The goal of these studies is to understand how participants understood the intervention or the technology of measurement or to understand how the intervention was delivered.

Example—Although EMDs have become the recognized standard for adherence assessment, little research has been conducted to assess the problems that researchers and participants encounter in their use and the potential threats these challenges may pose to the validity of study findings. As part of a randomized controlled trial on the effect of a home-based nursing intervention on combination ART adherence, Bova and colleagues[44] sought to explore the logistical problems associated with the use of EMDs. Their goal was to use descriptive data to determine if the way in which research participants used EMDs could influence study results and to develop ways of improving the data obtained from the use of this technology.

Methods Selected—The researchers developed a “descriptive, exploratory” study that collected side talk from research participants about problems they encountered in using the EMDs. They then administered a short, 5-item, open-ended set of questions in a face-to-face interview to assess the way participants use EMDs and conducted informal interviews with the research staff about the challenges they encountered using this technology.

Findings—The authors found that more than a third of the 128 people in the sample admitted that they did not use their EMD consistently. Forty-one percent reported taking out more than 1 dose at a time, and 26% reported opening the EMD but not taking the medication. Interestingly, an unspecified number of research participants report that the EMD actually helped them to remember to take their medications, thereby, constituting a type of unintended intervention.

Significance—The authors used qualitative methods to discover how an EMD was used in the context of a research trial and described the potential challenges this posed to the validity of results dependent on EMD data. They suggested that an EMD may underestimate actual adherence and urge that it not be used exclusively when assessing adherence.

QUALITATIVE RESEARCH ON ANTIRETROVIRAL THERAPY ADHERENCE: A REVIEW OF THE LITERATURE

Review Strategy

To understand how qualitative methods have been used in ART adherence research and the contributions they have made, we conducted an extensive search for English-language

publications describing studies using any type of qualitative method to examine adherence to ART (monotherapy and combination treatment). We used PsycINFO, Anthrosource, AIDS Line, and MEDLINE to locate articles published in refereed journals through January 2006 that contained some combination of the following terms: (1) *HIV, human immunodeficiency virus, AIDS*, or *acquired immunodeficiency syndrome*; (2) *adherence, compliance, highly active antiretroviral therapy, HAART, antiretroviral therapy*, or *ART*; and (3) *qualitative or grounded theory, focus group, content analysis, narrative, conversation, discourse, stigma, disclosure*, or *policy*. In addition to the electronic search, we reviewed by hand the bibliographies of relevant articles identified in the search and consulted with experts in the field. In some cases, we contacted authors directly to obtain an article or ascertain the eligibility of an article. We limited our search to published articles or in-press manuscripts and did not include studies for which only an abstract had been published and from which we could not abstract appropriate information about methods and results or obtain them from the authors. Conference abstracts were excluded. From an initial list of more than 80 citations, 66 met the a priori selection criteria.

Data Abstraction

Using standardized coding forms, we abstracted information from each published article. A pair of reviewers coded the information, and discrepancies were reconciled via discussion. Each study was coded for study purpose, sample, setting, type of qualitative method used, whether adherence was assessed (including the method used to assess adherence), adherence-related findings, and contributions to the field.

Study Characteristics

As seen in Table 2, the oldest of the 66 studies was published in 1995 and 6 were in press as of 2006. Of the 53 that reported their location, most (84%) were conducted in the United States. Slightly more than half (53%) were conducted in clinics, 17% in community settings, 3% in the clinic and community, and 3% in patients' homes. Most were based on convenience samples, with the baseline total population number ranging from 1 to 337 (median = 50). In terms of gender composition, 77% involved men and women, 17% women only, and 6% men only. Most studies involved a multiethnic sample, but 7% focused exclusively on African Americans, 2% on Hispanics, and 2% on Pacific Islanders. Most (81%) of the studies focused exclusively on patients, 9% on providers, and 10% on both. In terms of study methodology, 77% of the studies used a single qualitative method, 9% more than 1 qualitative method, and 14% a mixed-method approach.

Topics

The topical focus of the studies varied considerably. For the purposes of our review, we grouped them into 4 primary areas of inquiry: challenges, barriers, and facilitators; adherence practice; values and beliefs; and lived experience.

Challenges, Barriers, and Facilitators—This was by far the most common topic, with 34 studies focused on this topic and 16 looking at it as the sole topic of investigation. Studies in this group mainly elicited patient-identified factors and considered the influence

of different contexts on these factors, such as gender, race/ethnicity, age, substance use, mental illness, and homelessness.

For example, Wood et al[49] noted the importance of interpersonal relationships for women on ART as a barrier and a facilitator. Among African-American women specifically, substance use and a history of sexual abuse affected ART adherence.[50–52] In a report by Murphy et al,[51] Spanish speakers identified experiences with many of the same barriers and aids to antiretroviral medication adherence as other groups, but they cited cultural and language barriers as well. In another example, researchers reported that patients believed they had to take their medication with food. Research on pediatric samples suggested that a multifaceted approach to HIV care is likely necessary, given that children and youth need a personal support system, stable housing, and transportation.[53] Among repeat substance abusers, psychosocial factors found to be relevant to treatment acceptance and adherence included whether they sought social support or not and relapse to substance abuse.[54]

International work on challenges, barriers, and facilitators, mainly conducted in the past few years, indicated that external and structural factors seem to play a larger role in patients' abilities to adhere to ART than they do in Western countries. For example, work in Botswana found that the greatest barriers to adherence were finances, stigma, distance to clinics, and side effects, with cost cited as the major barrier.[55] Similarly, in Uganda, the initiation and impact of antiretroviral medication on health status were connected to the finances of the patients and their families;[56] the inability to purchase and secure a stable supply of medication was a major barrier to adherence.[57]

Adherence Practice—The second most common topic was adherence practice (the sole focus of 9 articles and the joint focus of 17 articles). These studies specifically examined the act of pill taking and other adherence behaviors, with the goal of understanding circumstances, rationales, factors, and individualized models that influence daily decisions about adherence. They included research on the initial decision to begin ART and the repeated subsequent decisions to initiate or discontinue medication.[41,46,58] Rather than global assessments of adherence based on self-report, EDM, pill count, and pharmacy record data, these studies focused on individual and idiosyncratic understandings of adherence. Findings indicated that patients' adherence decisions are continually renegotiated[41] and that patients engage in numerous practices to get themselves to take their medications.[59] Jones[58] concluded that successful medication-taking strategies were developed and refined over time, requiring time and energy. Patients in that study would decipher and translate the prescription, initiate an individualized plan of care, and then keep a list of their medication. Ryan and Wagner[39] found that daily routines were vital to "routinizing" adherence (ie, integrating adherence into daily routines and adjusting to changes without lapses in adherence).

Values and Beliefs—Fourteen studies focused on how values and beliefs influence medication taking (although only 1 study focused solely on this topic). Representative work from these studies indicates that patients may skip their medications if they plan to use drugs because of a belief in the toxic interaction of ART and street drugs.[60] Folk models about the way ART works may influence people's adherence practice by encouraging self-

regulation[61] if they believe the medication is toxic[62,63] or absolute fidelity to the physician's directives if they have complete trust in the physician.[64] Beliefs may influence whether people even initiate ART, deterring them if they hold ideas about conspiracy theories.[62] Remien et al[65] found that one of the strongest factors associated with adherence was belief that adherence was essential to health and that not to be adherent would lead to sickness. Values and beliefs are structured by culture; hence, this topic is a key element of cross-cultural studies of adherence.[55–57,66]

Lived Experience—Seven studies focused on lived experience, which was the sole topic of 3 studies. The notion of culturally patterned lived experience, a concept widely used in research on chronic illness and in gerontology, eschews placing disease at the center of the study in favor of examining wider contextual social factors. Such contextual factors include social relations, meanings, beliefs, and events identified as salient by an individual to determine the weight and meaning of the disease in his or her life and its relation to adherence behavior.[67] In a useful example of this approach, Wrubel et al[68] stated their investigation of lived experience as discovering "what is involved in the daily life experience of giving or supervising a child's HIV medication (ie, adherence practices) in order to clarify, in more dynamic terms than is often found in adherence research, what promotes or impedes adherence." In their study of how ART was connected to maintaining the patient's overall lifestyle, Ware et al[69] noted that the social process of stigma forced patients to balance their desire to pursue social relationships against the demands of safeguarding their health through good adherence, resulting in their marginalization and loneliness. They concluded that people with HIV do not routinely subordinate other social and personal needs to maintain adherence; hence, long-term adherence support must address the social contexts of patients on ART. Reback et al[70] found that participants in their study used coping strategies to re-establish control over their lives. Specifically, planned nonadherence during periods of substance abuse was a strategy patients used to cope with demanding HIV medication schedules by reducing adherence while using methamphetamine. Nonadherence was also attributable to fears of interaction effects from mixing methamphetamine with HIV medications. Overall, the work from a lived experience perspective suggests, as Remien et al[65] advocate, that one must analyze the complete person when attempting to understand adherence practices.

Other Topics

Health Care Professional Experience—Six studies addressed the topic of health care professional experience, such as that by Sowell et al,[71] which defines future research priorities in ART treatment based on interviews with 317 nurses, and that by Roberts and Volberding,[72] who explored the diverse ways that physicians communicate with their patients.

Patient-Provider Relationship—The patient–provider relationship was the focus of 5 articles, including a Canadian study indicating that patients believed their relationships with their providers influenced their adherence.[64]

Usability—Three reports addressed usability, 1 on the perceived clarity and level of difficulty associated with self-reported adherence measurement tools,[73] 1 on EDM,[44] and 1 on the acceptability of a better tasting version of didanosine.[59] Qualitative methods can be used to assess the usability of intervention materials through usability testing. They can describe and analyze the practices, preferences, and behaviors associated with using an adherence intervention or tool and the contexts in which its use takes place. Usability is the quality that is present in a web site, computer application, or other materials that takes into account the users' needs and abilities, the tasks they need to be able to do, and the surrounding environment in which they are trying to do it. In a study of the acceptability of mandarin orange–tasting didanosine, Reynolds and colleagues[59] discovered that although patients found the taste more tolerable, they also engaged in numerous strategies to attenuate the experience of taking the medication. The study documented the struggle that patients engage in to remain adherent and suggested that future drug trials include patient experience with medication as part of the assessment of medication impact.

Use of Qualitative Methods to Assess the Validity of Research Results—Six studies focused on assessing the validity of research results. Qualitative methods are able to provide confirmatory data to support intervention findings, to question their validity, or to identify areas in which problems may have occurred in implementation. This topic includes construct validity and intervention fidelity.

Decision Making—The three studies looking at decision making included a report by Gerbert et al,[74] who found that the main factors affecting providers' decisions about when to start combination therapy were the risks versus benefits of delaying therapy and the patients' health status, readiness to adhere, and treatment preferences. Providers in this study acknowledged that they lacked the resources to prepare patients to begin therapy and to enhance adherence and were anxious about making decisions under conditions of uncertainty and concerned about patient health outcomes.

CASE STUDIES

The following 2 case studies illustrate rationales and strategies for using a qualitative design or method to address ART adherence research.

Case 1: What Is a "Missed Dose"?

Accurate assessment of adherence is a central concern in the clinical care of people living with HIV and in research investigating medication efficacy. Valid adherence measures are also crucial to our ability to understand predictors and correlates of adherence behavior accurately.[75] Although considerable attention has been directed to the validity of different measurement techniques, technologies, and metrics,[76] less has been paid to a central construct in these assessments: the conceptualization of a "missed dose." There is no shared agreement, or guidelines, on the proper action to take in response to a missed dose. Determining when a dose is missed affects the accurate measurement of adherence through self-report; it also has implications for adherence behavior because of patient beliefs regarding the appropriate response to a missed dose. Although there has been some work

attempting to elucidate the relation between dose-time error and virologic outcomes,[77] more is needed.

In a longitudinal study of combination ART adherence among 150 African-American women and men, Sankar et al[81] conducted 3 self-report adherence measures: the 3-day recall,[78] the 30-day recall,[79] and the visual analogue.[80] One challenge revealed by interview side talk was that patients were unsure how to report medications taken late. This emerged because participants asked interviewers to clarify for them at what point they should consider medication taken late to be missed. Such expressions of confusion were accompanied by concerns about what to do if a dose was missed. How late could a dose be and still be taken? In response to these widespread expressions of confusion, a short instrument was developed combining 10 open-ended and close-ended items to explore the notion of a missed dose and its consequences. To understand all perspectives regarding this question, the same questions are asked of the participants' physicians and their medication inserts were examined (see the article by Sankar et al[81]).

A subgroup of 45 study participants and their physicians were administered the instruments. Results reveal large variability in conceptions for patients and physicians as well as significant differences between the 2 groups. Patients reported a stricter definition of missed dose than clinicians: 55% of patients defined a pill-taking delay of 6 hours beyond the prescribed dosing time as constituting a missed dose. In contrast, only 1 physician agreed with this assessment. More than a third of patients thought the proper response to a missed dose was to skip it completely, whereas only 12% of clinicians agreed. These findings challenge the construct of missed dose used in self-report adherence instruments. They revealed wide variance in the concept of a missed dosed as understood by patients and physicians and the proper actions to be taken in response to a missed dose. These findings have implications for adherence assessment, patient adherence, and patient clinical management.

Lessons Learned—The logic and issues participants consider in responding to questions differ from those implicit in existing self-report measures. In some cases, this led respondents to answer questions differently from the manner intended by the research design.

In conducting clinic-based research, researchers cannot assume that an understanding of the issue under study is shared among the clinicians or that the treatment recommendations are standardized even within a single clinic. The potential diversity of clinical understandings and practices needs to be included in the research design, when appropriate.

It was beyond the scope of the research to design a new adherence assessment based on the findings. Instead, the understandings from the supplemental qualitative protocol were integrated into probes that interviewers utilized to assess the criteria research respondents used in responding to the self-report instruments.

Case 2: Assessing Intervention Fidelity

For some combination ART adherence interventions, the interventionists' skills and other aspects of intervention implementation may be critical to improving medication taking.[82] Inconsistent delivery of an intervention may lead to a false-positive or false-negative outcome because of lack of treatment fidelity.[83] Indeed, one cannot be sure that an intervention adheres to its protocol in the absence of some evidence of treatment integrity.[84,85] Without treatment fidelity, in a study that does not show treatment efficacy, it is unclear if this is attributable to lack of efficacy or because the treatment was not delivered as intended, also know as a type III error. In studies in which an effect is found, without demonstrated fidelity to the treatment protocol, it is unclear what intervention has been tested.

Qualitative analyses of intervention sessions can be used to assess fidelity to an intervention protocol. In some approaches, such as motivational interviewing, adherence to the intervention involves maintaining fidelity not only to the specific steps of a protocol but to a particular style and quality of interpersonal interaction. In such a case, qualitative analyses of the quality of the processes of interaction may be particularly useful. For example, in a study of a motivational interviewing-based intervention to enhance combination ART adherence, Thrasher et al[47] used the motivational interviewing skill code (MISC), a structured assessment instrument developed at the University of New Mexico,[86,87] to provide detail about the process of motivational interviewing (MI) conducted in the intervention. By using the MISC, they were able to provide evidence of the extent to which the intervention—and counselor—adhered to the MI spirit and demonstrated a reasonable level of MI skill. A small sample of training studies suggests that changes in MI counselors' behaviors occur after training, suggesting that assessing quality of counseling over time is important.[88–92] In addition, by assessing whether specific aspects of the quality of the MI counseling were associated with combination ART adherence, they were able to begin to shed light on what aspects of MI quality may be more important than others.

Thrasher et al[47] conducted process analyses of recorded brief MI sessions used during a randomized controlled trial to improve antiretroviral adherence among a subsample of 47 HIV-positive patients attending a university-based infectious disease clinic.[47] In those analyses, they sought (1) to evaluate the quality of audiotaped MI sessions using MISC quality measures and (2) to explore whether MISC quality measures were associated with combination ART adherence. On 3 of 5 benchmarks, most MI sessions achieved the targeted quality level: 100% achieved them for MI-consistent statements, 85% for complex reflections, 63% for reflections-to-questions ratio, 44% for global therapist rating, and 19% for using open-ended questions. Combination ART adherence was positively associated with "affirming statements" ($r = 0.39$, $P = 0.01$), negatively associated with "closed-ended questions" ($r = -20.33$, $P = 0.02$), but not associated with any quality measures.

In the same trial, they also used free listing in interviews with study participants to assess fidelity to the intervention protocol.[46] At exit, they asked participants in both arms of the trial to freely list (1) things they liked about the sessions, (2) any goals that they had set, (3) any strategies that they had developed, and (4) things that had helped them achieve their goals. Two research assistants independently coded the responses to these free-list questions

using an iteratively derived manual of operationally defined codes (reliability >85% agreement). For most measures, a statistically significantly greater proportion of those in the MI group reported carrying out behaviors related to the MI intervention, such as setting a larger number of goals and strategies (particularly strategies related to medication taking).

Lessons Learned—Documenting MI quality was a critical piece in the ability to judge the efficacy of the MI-based intervention they developed because it allowed them to demonstrate that any lack of effectiveness was not attributable to inadequate delivery of the intervention. Furthermore, process analyses revealed aspects of the counseling that were more closely associated with adherence. Thrasher et al[47] also learned that regular feedback and close monitoring of counselors by reviewing process evaluations in an ongoing manner during the trial helped to facilitate the maintenance of treatment fidelity and MI quality.

NEXT STEPS: ADVANCING THE STATE OF ADHERENCE RESEARCH TOPICS AND METHODS

Our review of the qualitative literature addressing ART adherence uncovered several critical areas in need of further investigation. Each of these is well suited to qualitative methods.

Population-Specific Challenges to Antiretroviral Therapy Adherence

Most people with HIV live in resource-poor settings. As a result of global humanitarian efforts, ART is becoming increasingly available to this population. With this improved availability come increased challenges. The 2004 report by the Institute of Medicine ("Scaling Up Treatment for the Global AIDS Pandemic: Challenges and Opportunities") states that among other priorities, successful treatment of HIV in resource-poor settings requires that (1) adherence research priorities be informed by the perspectives of local researchers, health workers, and community representations and that they reflect respect for local cultures, and (2) the process of "scaling up" should rely heavily on "learning by doing," which includes ongoing evaluation and reassessment of interventions and programs to ensure that they are being carried out as intended.[93]

Qualitative methods can make 2 types of contributions in this area. First, they can identify and describe aspects of local culture relevant to adherence practice and meaning. Ethnography is an effective method for identifying and describing cultural values and beliefs and health care practices. Ethnography can serve as the basis for the development of more standardized qualitative methods such as open-ended or semistructured interviews. This research is needed to learn how to tailor what we have learned in industrialized countries to the support and maintenance of adherence in diverse resource-poor settings. A great variety of cultures may exist within a single country, especially among nations that were formerly colonies of European states. More significant groupings for understanding health care practices and beliefs may be ethnic or religious communities. Within the United States, significant distinctions exist among ethnic minority groups such as Latinos or Pacific Islanders that could influence adherence practices. We need to understand adherence practice in formal health care settings and informal contexts such as the home and community to achieve an understanding of the contexts and settings for adherence.

Qualitative methods can accomplish this goal. Second, qualitative methods can assess the cultural validity of constructs identified through earlier adherence research in other settings and the acceptability of research methods and technologies.

Understanding and Evaluating Adherence Intervention Outcomes

Qualitative methods have been used in the development and refinement of adherence interventions through formative work. As more interventions to improve adherence are developed and evaluated, we need to understand how to interpret outcomes. Qualitative methods can be used to ascertain whether an intervention was conducted as the designers intended. Exploration of participants' choices in adopting aspects of the interventions is needed. Understanding which aspects of an intervention had the greatest effect on altering adherence practice can help us to hone our interventions and make them as cost-effective as possible. Qualitative methods are well designed to make these determinations.

Longitudinal Patterns and Correlates of Adherence

Qualitative studies are needed to track how adherence varies with changes in individuals' lived experiences; in their social, economic, and psychologic contexts; and in health policy. In addition to understanding the challenges posed by the indefinite duration of ART in and of itself, another related issue is emerging: as people living with HIV on ART are maturing, how does this aging process affect their experiences in adherence with medication-taking? With HIV becoming a chronic illness and the likelihood that HIV-positive individuals, at least those in Western countries, may live well into old age, it is essential to identify and describe the evolution of patient adherence practices over time and to understand how these processes are located in the wider setting of living and aging with HIV. These studies must include attention to the experience of living over the long term with a highly stigmatizing disease. Finally, qualitative methods can be used to identify and describe cultural and structural barriers that impinge on adherence by impeding access to ART.

Role of the Patient-Provider Relationship in Enhancing Adherence

Research has established a link between the relationship that a patient has with his or her physician and adherence.[94] In resource-poor settings, where language, educational, and socioeconomic distance between practitioners and patients may be considerable, differences between patients and providers may serve to reduce the providers' ability to communicate with patients regarding the recommended regimen and reasons for the importance of adherence.[95] This may also be the case (although to a lesser extent) between practitioners in the United States and their ethnic minority patients, in whom well-documented disparities in HIV treatment and outcomes exist. We do not know exactly which aspects of the relationship influence adherence. Observational studies of clinic-based activities can shed light on aspects of patient-provider communication that might be used to improve ART adherence. In non-Western settings, the in-depth method of ethnography may produce the most detailed data concerning the way this relationship contributes to adherence.

Methods for Future Work

In reviewing these different topics, we suggest that researchers expand their repertoire of qualitative methods. Although we identified a number of studies that used qualitative methods in assessing aspects of ART adherence, we noted that the qualitative methods used in most of these studies were limited to only a few particular approaches. Given the benefits of using qualitative methods in HIV prevention research, we believe that a broader palette of methods would only strengthen the contributions of qualitative methods to understanding ART adherence.

Methodologic and Conceptual Considerations in the Use of Qualitative Methodology

Researchers who are consider using qualitative methods in their research as a stand-alone methodology or as part of a mixed-method design might also wish to consider several points. As is true for all methodologies, researchers need to understand the appropriate application of a method and the technical considerations required to implement it effectively in a particular study. Beyond the design considerations, the contemporary science climate or paradigm also shapes the choice of methods.

Lingering skepticism exists among some researchers regarding the validity of qualitative research results because they are less common and less well understood in certain disciplines. Researchers considering adopting qualitative methods may wish to anticipate this and become familiar with the consensus statements by the NIH and National Science Foundation concerning the appropriate uses of, evaluation criteria for, and valuable contributions from qualitative methods.[96,97]

Awareness of and attention to the rigorous standards used for the evaluation of qualitative research should strengthen the case for using these methods. According to Strauss and Corbin,[27] good qualitative research is distinguished by the following attributes: an explicit description of the research questions; careful discussion of the method and rationale for sample selection; description of the analytic categories and their source in the empiric literature, theory, or data, as in grounded theory; and discussion of hypotheses that structure the design or emerge in the process of a grounded theory design.[98]

The validity of qualitative results and the acceptability of qualitative methods can be enhanced through adopting multimethod designs that provide an opportunity for triangulation through the use of multiple qualitative methods or through mixed methodologies that integrate qualitative and quantitative methods. When adopting qualitative methods, researchers need to attend to the rigorous criteria for high-quality research identified by national and international funding agencies as well as by experts in the field.

CONCLUSION

Qualitative research has been important thus far in ART adherence studies in revealing key features and behaviors that could not have been identified using quantitative methods alone. Nevertheless, many areas still remain in which qualitative methods are needed to shed additional light on our understanding of ART adherence.

Qualitative methods tell us about the values, beliefs, attitudes, relations, and practices that influence adherence. Thus far, qualitative methods have been used to elucidate 4 main areas of ART adherence. First, many qualitative studies of ART adherence have described the challenges, barriers, and facilitators of adherence at a time when little was known about what it was like for patients to take combination ART. As those experiences change over time (as regimens change and patients age) and as ART use expands to new regions of the world, new qualitative studies of barriers and facilitators to ART adherence are needed. Second, qualitative studies have been used to understand better how patients take ART, by describing the ART adherence practices of people living with HIV. Additional work to understand more subtle aspects of ART medication taking, such as dose timing errors, are needed, however. Third, we noted that several studies used qualitative methods to understand patients' values and beliefs regarding ART, HIV, and ART adherence. Again, as ART becomes more widely used internationally, comparable studies in new regions of the world are critical to the development and implementation of culturally appropriate adherence interventions. Finally, a few studies have been conducted to understand the lived experience of persons with HIV, more are needed.

The body of knowledge that we have developed with regard to these 4 issues in the context of industrialized countries may not be widely generalizable. Thus, research is needed to assess the applicability of existing knowledge to new cultural contexts and to create a body of knowledge that encompasses new settings and cultural contexts for antiretroviral adherence. The imperatives of expanding HIV care and treatment globally should not reduce the attention given to adherence in industrialized countries. Challenges remain, especially among ethnic minority populations.

Areas ripe for qualitative inquiry include understanding problems patients have in accessing medical care, particularly ART; stigma associated with HIV; detailed descriptions of doctor-patient interactions; and understanding more complex patterns of medication taking, including the changing dynamics of adherence as individuals mature and grow old with HIV. In addition, few studies have taken advantage of qualitative methods as a means to assess intervention fidelity or measurement validity or to inform the development of adherence measures. High-quality rigorous qualitative research can help to address these challenges. Future qualitative ART adherence research that pays even closer attention to the rigorous standards used for the evaluation of qualitative methods, such as those outlined by Strauss and Corbin,[27] should strengthen the knowledge base of issues influencing ART adherence.

ART adherence is critical to successful treatment of HIV and is a central component of the experience of living with HIV. The experience of taking ART and following medical recommendations is highly influenced by contextual factors on the intrapersonal, interpersonal, community, social, cultural, and economic levels. Rigorous qualitative methods provide an important means for gaining a rich in-depth understanding of the interplay of such factors on patient behavior and on the experience and meaning of being HIV-seropositive and taking ART.

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TABLE 1

Basic Types of Qualitative Methods

	Advantages	Limitations
Interviews		
Semistructured interviews	Standardized, allows for in-depth exploration of topics, covers set range of issues, tape-recorded	Transcripts require transcription for analysis, requires skilled interviewer to probe effectively
Open-ended interviews	Covers fewer topics but in greater depth, allows for exploration of new topics or undefined areas, responses closer to issues identified by interviewee as significant	Requires that interviewer thoroughly understand study goals to take advantage of interviewee responses with probes, difficult to standardize, time-consuming, transcription required
Informal interviews	Typically conducted in setting relevant to research topic such as clinic or informant's home, allows for greater candor, facilitates connecting interviewee's responses with behavior	No set pattern for length or content, difficult to record, can not be arranged in advance, uneven content across sample
Focus groups	Limited number of participants, set time frame, promotes the emergence of unexpected topics and findings, encourages group consensus concerning a topic	Requires special expertise, transcription time-consuming and challenging, intragroup dynamics may distort findings, covers limited range of topics
Observation		
Nonparticipant observation	Unobtrusive, allows for overview of research setting, provides data on social interaction and practices, provides data on context, provides background for interviewees' responses	Time-consuming, limited access, participant may alter behavior
Participant observation	Provides data on participant's experience, reveals actualpractice versus norms and ideals	More intrusive, inability to record or take notes during observations, not all settings and interactions may be accessible
Ethnography	Reveals participant's perspective on research questions and setting and explanations of observed data, "inside" information, informal protocols	Time-consuming, requires open access to setting, ethical issues may arise if researcher becomes quasiparticipant
Archival research		
Documentary research on limited access sources	Examines documents related to clinic organization, formal treatment protocols to provide the official picture of a setting	Requires access to clinic data, may require expertise to interpret Formal structure and rules may not reflect actual practice, requires interviews and observations to assess relation to research topic
Documentary research on open access sources	Popular culture texts such as newspapers, television, plays, movies, provides lay perspective on a research topic	Difficult to establish direct influence on research topic or representativeness
Medical record review	Objective comparison to self report and subjective Assessments	Interpretation may be complex requiring expertise (eg, determination of genotypic resistance or nonadherence), may be of uneven quality, depends on interviewee's involvement in health care, not consistent across data set, access difficult to obtain
Rapid ethnographic assessment	Combines several qualitative methods to provide quick yet accurate overview of a research topic, especially useful in settings with undefined parameters and where the key participants may be unknown	By virtue of the limited time horizon, the data provide only a limited understanding of a research topic

TABLE 2

Summary of Published Qualitative Studies of Adherence (N = 66)

Citations	n	%	References
By topic			
Single topics	48	74	
AP	9		41,59,99–105
CBF	17		45,50,52–54,106–117
CVB	4		43,62,118,119
DM	3		74,120,121
IF and U	6		44,47,102,122
LE	3		39,69,124
PE	4		71,72,125,127
PP	2		127,128
Multiple topics	18	28	
AP, CBF	3		58,63,129
AP, CVB	1		39
AP, LE	1		130
CVB, PP	1		64
AP, CBF, LE	1		70
AP, CBF, CVB,	1		131
CBF, CVB	6		55–57,66,132,133
CBF, PE	1		49
CBF, PP	1		134
LE, PE	1		135
LE, PP	1		65
By method			
Single method	50	78	
FG	19		50,59,71,73,74,100,101,103, 106–108,112–115,117,121,133,134
UI	5		43,58,62,64,104
EG	1		56
SI	11		47,49,54,71,73,123,126,130,132
II	12		39,68,69,74,102,116,119,125,128, 129,131,136
CA	2		41,52
Multiple methods	6	9	
II, EG	1		124
II, SI	1		66
II, FG	1		45
II, UI	1		110
FG, UI	1		70

Citations	n	%	References
UI, SI	1		118
Mix: quantitative and qualitative (type described below)	9	14	
UI	2		99,118
SI	5		57,64,109,120,127
FG	2		64,122

AP indicates adherence practice; CA, content analysis; CBF, challenges, barriers, facilitators; CVB, cultural values and beliefs; DM, decision making; EG, ethnography; FG, focus group; II, in-depth interview; IF, intervention fidelity; LE, lived experience; PP, patient-provider relationship; PE, health care professional experience; SI, semistructured interview; UI, unstructured/open-ended interview; U, usability.