

ADOLESCENT HEALTH BRIEF

Video Intervention/Prevention Assessment: A Patient-Centered Methodology for Understanding the Adolescent Illness Experience

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Objective: To better understand the issues and needs of adolescents with chronic health conditions, the Video Intervention/Prevention Assessment (VIA) integrates video technology with qualitative research methods to obtain a patient-centered perspective on illness and health care.

Methods: Young people with chronic disease are interviewed for condition-specific verbal reports (CSVRs) of their medical and psychosocial histories. Standardized health-related quality of life (HRQL) instruments are administered. Trained to use video camcorders, participants record visual narratives of their illness experiences. They document their daily lives, interview families and friends, and record personal monologues regarding their observations, behaviors, understandings, and beliefs about their disease. On completion of the visual narratives, HRQL is again evaluated. Verbal, scaled, and visual data are analyzed from three perspectives: medical, psychosocial, and anthropological. Data from the CSVRs, HRQLs, and visual narratives are triangulated to validate and enrich findings.

Results: Investigating the illness experience from the adolescent patient's perspective, the VIA method was pilot-tested with children and adolescents with asthma. As a research tool, VIA found environmental risk factors, medication adherence problems, and outcome-affecting

illness beliefs and psychological states that were not identified by standard clinical tools. As an intervention, VIA showed that it may be an effective tool for health-related environmental surveys. Participants' condition-specific quality of life showed measurable improvement after the self-examination process of VIA. As communication, VIA made apparently counterproductive patient behaviors understandable by showing them in context with the adolescent's experience of illness and health care. VIA can enhance medical history-taking and management strategies, improve adolescents' self-management skills, and educate clinicians, families, and students of the health care professions about the realities of the adolescent living with a chronic health condition. © Society for Adolescent Medicine, 2000

KEY WORDS:

Asthma
Chronic disease
Health education
Medical anthropology
Patient-centered research
Qualitative methods

Improvements in medical knowledge and technology during the latter half of the 20th century have significantly reduced morbidity and mortality from acute diseases. Unfortunately, many chronic diseases have not benefited from these advances, with some, such as asthma, showing consistent increases in prevalence, morbidity, and mortality (1). Health conditions that require long-term medical management can have different outcomes in clinically similar patients. Patients' living situations, behaviors, and

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Manuscript accepted February 4, 1999.

The full text of this article is available via JAH Online at <http://www.elsevier.com/locate/jahonline>.

life experiences have a profound effect on their well-being and their ability to adhere to medical plans. Clinicians may be unable to intervene effectively if they do not understand how patients live with chronic health conditions in their daily physical, psychological, and social environments.

We developed Video Intervention/Prevention Assessment (VIA) based on the reasoned assumption that if clinicians were more aware of patients' daily experiences living with disease, they could provide medical care that was more responsive, sensitive, and effective. Building upon established qualitative research methods (2,3), VIA collects data in the form of patient-generated visual narratives, personal "video diaries" of living with a medical condition. Video was chosen on the assumption that children and adolescents who are brought up with television are comfortable with technology and may have more ease and fluency in relating their personal narratives in an audiovisual, rather than solely verbal mode.

Video Intervention/Prevention Assessment is based on visual anthropology (4–6), the study of people and the human condition through images, ranging from cave paintings to broadcast television. Still photographs (7) and motion pictures (8) have long been used as tools for ethnographic study by an outside observer. Recent improvements and miniaturization of imaging technology now allow researchers to place cameras in the hands of the people whose lives are being studied (9). Trained only in the rudiments of making the camera work, study participants produce naive images, amateur in quality but containing a first-hand rendering of their experiences. VIA builds on techniques of participant-created visual research developed with Navajo (10) and adolescent girls in a Philadelphia mental health clinic (11,12) to collect patient-generated visual narratives, focusing on their experiences of illness, health, and health care. Through visual documents created by research participants, we may realize a more direct understanding of people, their life experiences, and their perceptions of those experiences than may be afforded by data collected and controlled solely by the researcher.

Research Methods

Sample Selection

In qualitative inquiry that investigates small populations in great detail, it is critical to work with research participants who most accurately represent the population being studied. This issue is addressed

by selecting exemplars (13), individuals in whom observable phenomena represent the general phenomena of investigative interest. Applying this concept to health research with VIA, we recruit exemplars who meet clinical diagnostic criteria and represent the diversity of gender, race, ethnicity, culture, and socioeconomic characteristics of the broader population affected by the health condition studied.

The VIA pilot study enrolled 21 young people diagnosed with moderate or severe asthma based on 1992 National Heart, Lung, and Blood Institute criteria (14). Recruited from a tertiary care pediatric hospital and an inner-city health center, there were 11 males and 10 females, ranging in age from 8 to 25 years old. Ten participants were black, nine white, and two of mixed race. Six were of Hispanic ethnicity.

Informed Consent

In developing and refining the VIA protocol for the pilot study, extended discussions occurred among the research team and between the principal investigator and the Children's Hospital Committee on Clinical Investigation (institutional review board) regarding the risks and benefits of this new mode of inquiry. Video as data presents unique issues in both the data collection and analysis phases of research. Concerns included whether video-making placed participants at risk, what to do if abuse or neglect were observed on tape, and how to protect the participants' privacy while still permitting them to share their life experiences freely. Risks of video-making to the participants were determined to be minimal if certain precautions were observed.

The VIA participants were advised to be accompanied by an adult outside of safe environments such as home or hospital. Camcorders were covered in black tape to make them less obtrusive and less attractive to potential thieves. The informed consent stated that abuse or neglect observed on video would be reported as mandated by child protection laws. The potential loss of privacy to participants, their families, and friends portrayed in the visual narratives represented the most complex risk. Although names and other identifiers can be removed from other types of research data, video records both images and voices that can be recognized. For the pilot study, the committee determined that with appropriate consents and releases obtained from the participants, the VIA process did not constitute surveillance or result in an invasion of privacy because

the participants had complete control over the making of their visual narratives. The informed consent document stated that visual narratives would not be viewed by anyone except members of the research and clinical teams without the participant's permission. On completion of their visual narratives, participants were given copies of their video to view and, if they wished, edit. At that time, a second written permission was requested to release the use of their recorded image and voice for research presentations, electronic publication, or teaching. The Children's Hospital Committee on Clinical Investigation approved the VIA protocols for the pilot study of asthma.

Data Collection

The VIA data consisted of three major components: (a) Condition-Specific Verbal Report (CSV), (b) Health-Related Quality of Life (HRQL), and (c) visual narrative.

The CSV is a comprehensive medical history and psychosocial assessment administered as a face-to-face interview in a clinical setting. A rigorous analog of the gathering of disease-specific information that occurs in an initial medical evaluation, the CSV focuses on assessing the condition being investigated and is standardized within each study. The CSV used in the VIA pilot study was developed with clinicians and social workers who cared for children and adolescents with high-risk asthma. The CSV is designed to elicit information on the participant's general and condition-specific medical status, management issues, and health care needs. The medical history addresses symptomatology, morbidity, medications, self-management, and level of health knowledge. The psychosocial assessment explores the social, psychological, and emotional aspects of a patient's illness and disability, including: (a) home, school, and/or job environments; (b) day-to-day activities; (c) relationships with family and friends; (d) access to and use of the health care system; (e) insurance status and financial barriers to care; (f) logistics and interpersonal dynamics of routine medical management, including relationships with health care providers; (g) response to medical emergencies; (h) quality of life; (i) the participant's understandings and beliefs about his or her health condition; and (j) the participant's psychological and emotional responses to the illness experience and the limitations that the illness imposes.

Health-related quality of life is measured with a standardized, previously validated instrument ap-

propriate to the age of study participants and the medical condition studied. The VIA pilot study used the disease-specific "Pediatric Asthma Quality of Life Questionnaire" (PAQL) (15), which measures the impact of asthma in three domains: symptoms, activity level, and emotions. The current VIA study of obesity uses a general health status instrument, the Child Health Questionnaire-Child Form 87 (CHQ-CF87) (16), developed and validated for children and adolescents between the ages of 10 and 18 years. Completed by the study participant, the CHQ-CF87 evaluates 12 health-related concepts: (a) physical functioning, (b) limitations in usual social roles owing to emotions, (c) limitations in usual social roles owing to behavior, (d) limitations in usual social roles caused by physical state, (e) bodily pain, (f) general behavior, (g) mental health (psychological distress and well-being), (h) self-esteem, (i) general health perceptions, (j) change in health, (k) family activities, and (l) family cohesion. As with the CSV, HRQL implements an instrument appropriate to the condition being investigated and standardized within each study.

The core data of VIA are the visual narratives, documentation by participants of their own illness experiences. Each participant is taught to operate a video camcorder, using a modified version of indirect teaching methods. Indirect teaching methods were developed by Worth and Adair (10) and refined by Chalfen (11,12) to obtain participant-created visual data that are not influenced by conventions of film-making style by teaching only the mechanics of using the camcorder to record video. After learning how to load tape, change batteries, and aim the camcorder at what they wish to document, participants practice shooting video, evaluate it with their instructor for technical issues, then modify their video-making in their own ways (17).

Provided with unlimited tape, VIA participants document their day-to-day lives for 4-8 weeks. Upon starting their visual narratives for the pilot study, participants were asked to "teach us about your asthma." Participants are encouraged to show their lives as they experience them. For example, in the VIA pilot, one 13-year-old boy showed himself playing catch in the back yard with his dogs, a 16-year-old girl recorded hours of dishwashing and housecleaning, and an 8-year-old boy documented a visit to the grave of his father. To record situations that relate to participants' diagnosis as well as common activities that could be compared among them, we provide participants with a standardized list of video assignments which instructed them to video-

tape: (a) tours of their homes and neighborhoods, (b) daily activities from morning until bedtime, (c) self-care and medical management, and (d) contacts with the health care system, particularly medical visits, documenting their and their family's interactions with clinicians.

The VIA participants were asked to interview family members, friends, teachers, coaches, clinicians, and anyone else with whom they had close contact, exploring that person's perceptions of and experience with the participant and his or her medical condition. Participants were provided a standard set of open-ended interview questions but were encouraged to add their own questions, and use questions as springboards for conversation about their health. In the VIA pilot study, standardized questions addressed the interviewee's understanding of the participant's asthma and the limitations it may or may not have imposed, attitudes toward and beliefs about the person with asthma, and personal observations and feelings about asthma. Finally, we asked participants to speak directly to their camcorders about their experiences, observations, and feelings living with illness. In the manner of a written diary, they were encouraged to relate the day's events, their responses to the events, and their reflections.

After completion of the visual narratives, the HRQL instrument was readministered to determine whether the self-examination process of VIA resulted in any change in disease-specific quality of life for the participants. The VIA pilot study implemented a single data collection module with each of the participants. In longitudinal VIA studies which observe changes in health and psychosocial status over time, the VIA data collection module, consisting of the CSVR, HRQL, and visual narrative, may be repeated at intervals appropriate to the subject of study.

Data Analysis

The VIA data took three basic forms: verbal, scaled, and visual. The verbal data from the CSVRs were transcribed. Key medical and psychosocial information that could be observed in the visual narratives were assigned codes indicating data categories such as medication use, environmental factors, or psychological response to disease. The scaled data from the HRQL instruments were entered into a statistical database such as SPSS (18) so that an individual participant's quantified health and psychological status could be correlated before and after the visual narrative process and compared with normed pop-

ulation data. The visual data of the participants' illness narratives were copied to VHS tape with superimposed readouts designating the participant, tape number, and time code in hours, minutes, seconds, and frames. Using these numerical codes, researchers could note and communicate the locations of specific observations on the videotapes. Video loggers viewed the visual narratives in real time and logged their video and audio content in detail on a standardized observation matrix (Figure 1). The VIA log sheet was designed to allow parallel observations of the same material by different loggers. These logs could be compared with each other to ensure diachronic interrater reliability (3,19,20). The video loggers noted: (a) which (if any) assignment was fulfilled, (b) an objective description of the scene, transcribing or paraphrasing verbal content such as monologues or conversations, (c) who was shooting the material (source), (d) time codes of the beginning and key moments of each scene, and (e) subjective comments on the tone and meaning of the scene in relationship to the VIA participant and his or her health status. Researchers used the frame-specific video logs as guides to locate scenes, interactions, and events for analysis.

Although video has been used for frame-by-frame microanalysis of extremely short behavioral streams (21–24), there is no precedent for analyzing extensive bodies of visual data that intermittently document continuous human behavior. VIA participants used images, sounds, and words to examine and share with clinicians their illness experiences, revealing the beliefs and behaviors that framed and affected their condition. Some experiences could be shown; some were more easily verbalized. Critical to the development of the VIA methodology has been the creation of a rigorous structure for analyzing the visual expression of patients' illness experiences, to understand what is shown as well as we understand what is told. For the VIA pilot, we built upon Chalfen's sociovidistic descriptive framework for the analysis of films made by adolescents (11) and snapshots taken by families (25) to design a VIA-specific framework for analyzing the visual data. Structuring the lives and experiences of those who made and were portrayed in the visual narratives, the VIA framework addressed general and condition-specific health issues as well as psychological, social, and cultural phenomena revealed in the visual data.

Guided by the video logs, a physician evaluated the visual narratives for health-affecting features of participants' physical and psychological environments, medical self-management, and the nature and

PARTICIPANT/TAPE ID# 07:09

VIA LOG SHEET

PAGE# 01

NAME AL

LOGGED BY JG

ASSMNT	DESCRIPTION/LOCATION	SOURCE	TIME CODE	COMMENTS
Doctor Visit	At the doctor's office watching Calvin get some shots. Angel gets his shots. Calvin teases him, "Look at Angel trying to hold the pain in!" Doctor: "Notice the mothers aren't in here to watch!" Dr: "What did you get for Christmas? Troy Aikman seems to be the big thing this year." Doctor listens to Angel's chest: "Were you running?" A:"No." Angel does peak flows: 450 (Dr: "It's better!") 400, 430	Angel Calvin	16:00:00:00 16:03:00:00	Calvin and Angel egg each other on a little, dealing with their discomfort by goading each other. What about the fathers? They both laugh a little at the corniness of the doctor's comments.
Daily Life	The sledding hill at the reservoir - Angel and Calvin climb the hill and sled down. They walk back to the camera. A: "I got hurt on that one."	Tripod	16:03:40:00	
Interview	Angel interviews best friend, Calvin, about Calvin's asthma - A: "Why do you think you have asthma?" C: "I don't know." A: "Do you wish your asthma could be gone completely?" C: "Sometimes I do, sometimes I don't." A: "Why?" C: "Attention."	Tripod	16:38:00:00	Angel and Calvin seem bored. Angel is reading the questions. Calvin is distracted. Insightful. Maybe he is more engaged than he originally appeared.

Figure 1. Standardized VIA Observation Matrix

quality of relationships with health care providers. A clinical social worker or other mental health professional identified and explored psychosocial themes and the nature of interpersonal dynamics around the participants' medical conditions. The social worker evaluated participants' psychological responses to their illness, coping mechanisms, and health-related behaviors. Social barriers to, and facilitators of, health such as ability to pay for medications and medical care; barriers to access posed by transportation, language, or culture; and social attitudes toward disease and health were assessed. An anthropologist applied visual anthropology to analyze how participants saw and synthesized their worlds and cultural anthropology to determine how they understood and made meaning out of their illness experiences.

Visual data were analyzed using (a) observational techniques (26,27) developed in sociology and anthropology; (b) narrative analysis (28-30), which determines patterns of meaning from the stories that

the participants tell; (c) grounded theory (31,32), an approach that develops analytical structure and meaning from the data rather than fitting the data to a predetermined theoretical structure; and (d) phenomenology (33-36), which analyzes how phenomena are understood by the individual and structured into beliefs which motivate behavior.

For the VIA-Asthma pilot, ATLAS.ti (37), a computer software package designed to organize and display large bodies of mixed types of qualitative data, was used to structure the analysis. Key investigators from each discipline (medicine, social work, and anthropology) met regularly with the research assistants logging and analyzing the data to discuss their analyses, validating observations and applying the theoretical frameworks of their disciplines to enrich and add dimension to the findings.

The three types of VIA data, verbal, statistical, and visual, were triangulated (38-40) (Figure 2) to compare, complement, and possibly contradict each

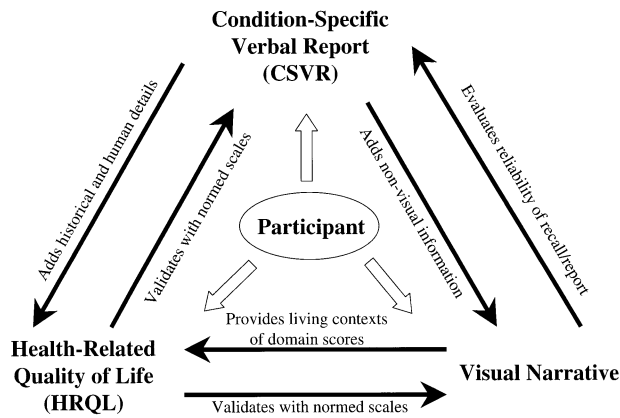


Figure 2. Triangulation of Video Intervention/Prevention (VIA) Assessment Data

other. The CSVs brought historic and human details to the HRQL scales that in turn validated the CSVs with standardized data from a normed instrument. The VIA visual narratives were compared with the CSVs to evaluate the participants' quality of recall and accuracy of verbal report. The CSVs added explicit and implicit nonvisible information to what was shown in the visual narratives. The HRQL scales provided quantified measures of physical and psychological health status against which the visual data could be interpreted, whereas the visual narratives provided a real-life context for the domain scores arrived at by the HRQL. As an example, visual narratives were evaluated by coding their findings in parallel with questions asked in the CSV interviews. If the initial interview question asked, "Who is the primary person responsible for your medical care?" the visual narrative was analyzed for the answer to the question that was shown. The different data types and analytical frameworks of the VIA method yielded a multidimensional understanding of the phenomenon being investigated. When individual analyses were complete, overall themes that emerged from the visual, verbal, and statistical data were identified and areas of consonance and dissonance noted. In addition to enriching data analysis, triangulation is a powerful means of validating qualitative findings (19,41,42).

Results

Results from the VIA–Asthma pilot, portions of which have been reported elsewhere (17,43,44), were rich and varied. The video documentation of participants' day-to-day lives and environments yielded different and more detailed data than had the med-

ical histories. A majority of the home and neighborhood tours done for the pilot study showed asthma triggers that were specifically asked about in the CSV interview but not acknowledged by the participants (43). Exposures to dust, mold, dander-producing animals, noxious fumes, and passive tobacco smoke that had not been elicited by the clinical interview were revealed in the participant-created visual surveys of their everyday environments. One video tour of a participant's home revealed that although his bedroom was "asthma-safe," the larger living environment of his house was overcrowded, with 19 people living in cluttered, dusty rooms, cockroach-attracting dirty dishes in the kitchen sink, and forced air heating.

Similarly, recording home medical management and visits to health care providers revealed a number of problems of which clinicians were unaware. Self-administration of medications was observed to be of variable effectiveness owing to participants exceeding recommended doses, self-discontinuation of medications without consulting a clinician, or, despite participants' many training sessions with nurses or health educators, ineffective technique with the metered dose inhaler (43). One participant demonstrated his inhaled steroid use by releasing it into the spacer, putting the spacer to his mouth after 5 s, then inhaling too quickly for proper deposition in his lungs. Another acknowledged that although she was well aware that prednisone had intervened on her near-fatal asthma exacerbation, the corticosteroid also caused her to gain 60 lbs, develop acne and stretch marks, and have dreams from which she awoke convinced that she had murdered someone. She hated what corticosteroids did to her and decided, against medical advice and without notifying her clinicians, to stop taking them.

Documented clinical visits revealed that several participants were unclear on the details of their medical plans. Unsure of the use and function of their medications, some participants were using anti-inflammatory drugs when short of breath and quick relief bronchodilators on a long-term basis. More important, they did not know or feel empowered enough to ask clinicians to clarify their management plans. Interactions between participants and their clinicians were often characterized by denial, rebellion, and negotiation. Complex power relationships between a patient and her physicians were eloquently revealed in the following clinic visit of an 18-year-old patient (ME) with her primary care doctor (PMD) and her asthma specialist (SP):

PMD: I have a real vested interest in keeping you off the steroids because I know how miserable they make you feel. However, they do something that helps you.

ME: (pointing at SP) SP over here, he's quick to pop me back on it.

PMD: I know he is, okay. But I've been negotiating on him, I've been working on him.

ME: I want to let you know you can write the scripts all you want, I won't do it.

PMD: Okay. Let me ask you a question. One of the things we do for people who are kind of wandering on the edge of needing it, and I've got him to agree to this, is try them every other day.

ME: No!

PMD: All right, so they whack you out even when you do them every other day?

SP: Have you tried them every other day yet?

ME: I don't want them. I told you. I called you and said to you, I'm taking myself off them. I meant that!

They discuss alternatives to the steroids that the patient has refused to take.

PMD: . . . whether Serevent would afford us anything . . .

SP: No, the problem with Serevent is . . . she'll die!

ME: Thanks. I hate when you say that!

PMD: (to SP): If we could, if you feel okay with that, maybe we should start some SloBid.

ME: Don't bullshit me . . . Now, do I get crazy dreams? Do I gain weight? Do I shake? . . . I don't trust you all on that level, especially you (points at SP). I'm being honest, I really don't trust you when it comes down to medications. I do not trust you all. There's a part of me that feels like I'm a guinea pig with you all. Even though it may not be that, that's how I feel.

The VIA interviews elicited important information about the experience and meaning of chronic disease in an individual's and a family's life. As an example of how the disease affects the family and family relationships, this is an interview conducted by an 11-year-old girl (DM) with her mother:

DM: Describe what happens during one of my asthma attacks.

Mother: Oh, first I panic, then I get you your nebulizer treatment. And, of course, I run outside and have a cigarette, which is the worst thing for me to do, but as long as I'm outside with the door shut . . . then I come in and I still panic and I rub your back and you keep saying, "Ma, don't get nervous, Ma. I'm okay, Ma."

DM: Okay, Mom! How do you feel during one of my asthma attacks?

Mother: Nervous, sad, worried . . . and mad. I still get mad.

DM: Mad at what?

Mother: I get mad because I just don't think you should have to have asthma.

Participants demonstrated a variety of belief systems and adaptive responses to living with asthma, ranging from disability to denial, from a sense of specialness to self-comforting behaviors (44). Asthma was transformed by its social context, with biomedically similar disease states yielding very different illness experiences and illness-related behaviors for participants in different psychosocial environments.

The most diaristic component of the visual narratives, the personal monologue, yielded insights on participants' emotional and psychological responses to their chronic condition. Lying in bed, preparing for sleep with her HEPA air filter running, an 18-year-old girl recorded this monologue:

You feel useless. You can't fight back. . . Can't breathe. And every time I had those, I was all alone. So, say like you're on the street or something. You don't know who to run to. You're very embarrassed of running to a person you don't know. It's already bad enough to run to a person you know, but to run to a person you don't know, oh my God! I've had to take a taxi or even taken the bus to the hospital, all by myself. And I got there and said, "Help me. I don't know what to do. Nothing's working." And I mean, you're like, you know there's five, or maybe ten minutes it takes you to get to the hospital, depending on where you were or whatever, are like five hours of gasping, of trying to breathe. You know it's, God, it's like the world's closing in on you and you want to scream, and you can't!

Psychological responses to living with chronic disease were related powerfully through the voices of VIA-Asthma participants. A sense of isolation from their peers, dysphoria about their bodies because of limitations imposed by asthma or medication effects, and fear of sudden death were prominent psychological themes that emerged from the pilot visual narratives (45).

In some cases, the visual narratives showed, rather than verbalized about, these responses. The stress of living with this unpredictable and dangerous disease is demonstrated powerfully by an 18-year-old girl who videotaped herself having an asthma exacerbation. For 4 long minutes, as her mother drives her to the emergency room, her breathing grows increasingly labored, fast, noisy. She puffs out her cheeks to open up her airways. Her eyes widen with fear. As her respiratory distress worsens, the observer's powerlessness is relentless. For clinicians accustomed to controlling disease, this sequence is difficult to watch, but it teaches and

builds empathy. This scene of unrelieved respiratory distress not only illustrates, but duplicates the helplessness, fear, and uncertainty with which many young people who have asthma live their lives.

Applications

Results of the VIA pilot study indicated three areas in which to implement the VIA methodology: as research tool, as clinical intervention, and as patient-centered communication.

VIA as Research Tool

VIA broadens the clinical research database beyond the patient-related medical history and the physical examination by showing disease *in situ*, in the context of the day-to-day lives and experiences of the young people who live with it. A camera in the patient's daily living environment presents an opportunity for observation of disease in its real-life manifestations. Clinicians often suspect that there are more health risk factors in a patient's environment than they are able to determine with a medical history, an assumption supported by the VIA pilot findings. The indiscriminate and uncompromising gaze of the camera was able to show what the selectivity of perception and memory may have filtered out of the patient's verbally reported medical history. If not asked about in a format that is aware of, and responsive to, the patient's lifestyle, a key risk factor may not be reported to the clinician. As an example, the asthma CSVr asked whether there are any smokers in the participants' homes. In most cases, this question was responded to in the negative, because avoidance of passive tobacco smoke is a key tenet of asthma self-management that is often problem-solved for the participant's home. However, significant exposure of the participants to passive smoke, at parties or other homes, was revealed in 63% of VIA–Asthma visual narratives (43). In light of these findings, the wording, approach, and breadth of clinical interview questions may be evaluated and redesigned to improve the sensitivity of the medical history to the realities of patients' lives.

With asthma, as with other chronic diseases, medications are a critical part of self-management, but patients' relationships with their medications can be complex and ambivalent. Asthma requires maintenance management when the patient is well, using medications from which patients derive no immediate palpable benefit. Through participants' self-doc-

umentation of their day-to-day lives with asthma, VIA revealed that 89% of the pilot participants had one or more significant failures of medication adherence (43). Less invasive than direct observation by researchers and less judgmental than dose monitoring or questioning of the patient, VIA allows young people to show the parts of their medical self-management with which they are having difficulty. As a result, VIA may be a more sensitive and specific tool for investigating problems of adherence to medications and management plans. When the real-life issues are understood from the patient's perspective, the clinician can partner with her to solve the problems, rather than falling into judgmental assumptions and an adversarial relationship.

Beyond revealing the observable features of the participants' lives, VIA can yield insight on the subjective experience of illness, the thoughts, feelings, and beliefs of young people dealing with chronic conditions. The psychological effects that can accompany chronic disease often contribute to long-term morbidity, either directly in the form of depression or disability disproportionate to the degree of disease, or indirectly in the form of poor adherence to medications or management plans that may result from emotional responses to illness. VIA can yield a more direct understanding of the psychological features and resulting health-related behaviors of chronic illness. This awareness can guide the development of clinical and psychosocial interventions to improve quality of life for these young people.

VIA as Intervention

The information yielded by VIA and the process by which the participant obtains it have shown the potential of VIA as a therapeutic intervention. Upon viewing their visual narratives, several participants discovered environmental asthma triggers that they lived with but had not noticed until they saw them recorded on video. One young man believed that he was living in a well-controlled, allergen-free environment because his bedroom had no carpet, it was kept animal-free, smoke-free, and spotless, and the air was filtered. Watching his house tour on video, he realized for himself that he entered his home through a room full of mold-producing leafy plants and spent a considerable amount of time in other microenvironments in his home that contained potent asthma triggers. Human perception is not absolute, but focused by attention and filtered by experience. People may not see features of their daily existence to which they are accustomed or that they feel cannot be

changed. The camera has no selectivity; it documents what is there. When the pilot VIA visual narratives were viewed, the distancing effect of the video allowed participants to discover for themselves health-affecting exposures in their daily environments to which they were previously oblivious. Supplied with an inexpensive, reusable camcorder and several dollars worth of videotape, a patient can generate a video survey of primary living environments in less than an hour, yielding a more accurate and complete picture than perception and memory allow. Viewed with a health educator or nurse, these surveys can catalyze environmental modifications by allowing patients to discover health risks for themselves and to develop individualized interventions with the advice of a specialist.

Used for over 30 years in psychiatry, video therapy has demonstrated the therapeutic effect of patient self-observation (46–48). With chronic diseases requiring long-term management, self-awareness may play an important role in health outcomes. Measurement of participants' HRQL before and after making visual illness narratives can indicate whether the self-examination of the VIA process results in a change in their general or disease-specific quality of life. Participants in the VIA pilot showed significant improvement in their asthma-specific quality of life after creating their visual narratives, but before viewing them or changing their disease management based on the research findings (49). The self-documentation and reflective feedback of creating a visual narrative of the illness experience may function as a therapeutic intervention with health conditions that require long-term self-management.

VIA as Communication

Medical inquiry is problem oriented and care is clinician driven. Patients present with a health concern or complaint. Clinicians function as biological detectives, diagnosing the problem through thoughtful, focused investigation that follows established patterns of medical logic. Management is based on biological principles, clinical experience, and research-proven effectiveness. Yet, the patient's understanding of disease is influenced by factors other than science. Ideal management from a clinical perspective may be unacceptable or not viable in the context of the patient's life. How patients experience and respond to disease is critical to their medical outcomes. By asking patients to show clinicians their realities and their needs by creating illness narra-

tives, VIA can be a powerful tool for improving communication.

Using phenomenology to understand how patients make meaning of their medical conditions, VIA's self-documented illness experiences can reveal participants' explanatory models of illness (28,50,51). These coherent belief systems, which may vary dramatically from clinical constructs, can powerfully influence patients' choices and behaviors. Much of the extant literature about the explanatory model of illness examines patients' beliefs about the origin and nature of their diseases. All of the participants in the VIA pilot related biomedically accurate explanatory models of the asthma disease process. Because they were patients with moderate or severe asthma at a major medical center, these findings revealed the effectiveness of the asthma education that they had received as part of their medical care. However, in this group, accurate knowledge did not translate into effective health behaviors because participants did not always believe that their asthma management plans would be effective or that the potential benefits were worth the side effects (52). These asthma patients' explanatory models addressed disease management rather than etiology. VIA was able to shed some light on the unclear relationship between health knowledge and behavior because it looked broadly at participants' illness perceptions, rather than limiting itself to a focused inquiry into explanatory models of disease origins.

The conflictual interaction of ME with her doctors, characterized by frustration, rebellion, and negotiation, is illustrative of many noncompliant patients. ME is an exemplar of the difficult patient; yet, when seen in context with her larger life and her explanatory model of asthma and its management, her refusal to take steroids despite the clear need for them becomes understandable. More important, when VIA allowed her experience with illness and its management to be understood and her wishes heard, ME felt respected as a partner in her health care and ultimately negotiated a reasonable management plan. The patient-clinician relationship is built on the premise that the clinician has valuable knowledge and skills to impart to the patient. If clinicians' recommendations do not fit with their lifestyles, beliefs, or perceived needs, patients may not always feel able or willing to question those recommendations, but instead may simply not follow them. The authority conferred by the clinician's training is not challenged by the patient and the power differential between clinician and patient inhibits open, effective communication (53). VIA shifts this power differen-

tial, providing a mechanism for patients to teach clinicians about their illness experiences, giving them a voice in their own care.

Conclusion

Providing a unique patient-centered view of the world of adolescents and their experience of illness, VIA can be an effective means of expanding our knowledge of disease beyond the clinical setting. In a sense, it uses contemporary communications technology and methods of qualitative inquiry to return to the traditional house call. The illness narratives that the young people who live with asthma produced yield a body of important information about this disease that could not have been obtained in any other way. The VIA method obtains data through standard of care clinical evaluations, established health status measures, and patient-created visual narratives of their illness experiences to constitute a multidimensional, complex, and real portrayal of living with illness. In the future, this innovative method can be applied to many disease states and health risk behaviors to further our knowledge, challenge our preconceptions, reframe our questions, and ultimately help us to develop a more complete understanding of the adolescent illness experience.

Limitations to the VIA method include the considerable costs of videotape, camcorders, and professional video recorders for frame-specific data analysis. VIA is a labor- and time-intensive technique. The research coordinator needs to devote a significant amount of time to supporting and encouraging the participants to complete their visual narratives in a thorough and timely manner. Detailed analysis often requires two to four times the actual video running time to evaluate the visual data. As a result, VIA is best implemented in a research setting or for comprehensive evaluation of complex patients. Because VIA is resource intensive, it may be difficult to study sample sizes that can achieve statistical significance. However, in-depth investigation of exemplar participants can inform researchers to needs and issues that exist in the broader population that they represent, generating focused questions for further study.

Through the youth-friendly medium of video, VIA elicits information, objective, experiential, and reflective, about young people's lives with illness. Some experience can be verbalized; some is more easily shown. Using images, sounds, and words, VIA participants examine and share with clinicians their illness experiences, revealing beliefs and behaviors that frame and affect their condition. Because pa-

tients create their own visual narratives, VIA eliminates the problem of reactivity to an outside observer and may show a more accurate picture of how young people understand and live with disease. The objective information that the video captures is enhanced and enriched by the subjective dimension of the patients' perceptions. VIA has the potential to influence more than the patient-clinician relationship through its patient-centered investigation of health issues. Questions raised and theories generated by VIA generate new avenues of inquiry for medical and public health researchers in areas such as medical adherence, health care delivery, and prevention program design. By asking patients to teach clinicians about their experiences living with medical conditions, VIA can be a potent and humanizing tool for teaching the science and the art of real-world healing.

This research was presented in part on March 5, 1998, at the Society for Adolescent Medicine (SAM) meeting in Atlanta, Georgia, at which Dr. Rich received the SAM New Investigator Award for this work. The development and pilot implementation of the VIA methodology was funded in part by the John W. Alden Trust, Arthur Vining Davis Foundations, Deborah Munroe Noonan Memorial Fund, Gerondelis Foundation, Agnes M. Lindsay Trust, and the Mary A. and John M. McCarthy Foundation. The authors thank Margaret Connors, Ph.D., and Ellen Goodman, L.I.C.S.W., for their contributions to the development of the interview instruments used in this study; Lynda Schneider, M.D., for her help with the pilot study of asthma; and Mariah Almond, Colum Amory, Huguette Arza, Jackie Chandler, Jessica Heimbaugh, Michael Melone, Allison Nagy, Dharani Reddy, Adrienne Lyons Ruth, Lauriann Serra, Amanda Stein, Stacy Taylor, Krishna Upadhy, Mahlet Woldemariam, and Sheldon Zink for logging the video data. The authors are particularly grateful to Elizabeth R. Woods, M.D., M.P.H., and S. Jean Emans, M.D., for their support during the development and implementation of VIA; and to Arthur B. Elster, M.D., and Gail B. Slap, M.D., for their critical reading of the manuscript. Finally, and most important, the authors thank the young people who shared their illness experiences through VIA.

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