Self-Management in Pediatric Inflammatory Bowel Disease: A Clinical Report of the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition

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ABSTRACT

This clinical report aims to review key self-management and adherence issues in pediatric inflammatory bowel disease (IBD) and to provide recommendations for health care providers regarding evidence-based assessment and treatment approaches to promote optimal self-management. Self-management difficulties in the form of nonadherence to treatment regimens are common in pediatric IBD and are influenced by various disease-related, individual, family, and health professional relationship factors. To promote adaptive self-management, health care providers are encouraged to adopt a long-term preventive orientation, which includes routine screening of barriers to self-management and nonadherence in the context of routine clinic appointments. The use of a multimethod approach to assessment that incorporates objective measures (eg, pill counts or bioassays) may be particularly advantageous. Individualized treatment approaches that incorporate evidence-based practices, such as providing written treatment plans and offering opportunities to practice and receive feedback on skills, may help to ameliorate minor self-management concerns; however, more severe or chronic self-management problems may require a referral for behavioral health intervention. Additional research to broaden our understanding of self-management in domains beyond medication adherence and to evaluate the effect of clinic-based interventions is imperative.

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Pediatric inflammatory bowel disease (IBD) is a challenging condition from both medical and behavioral perspectives. Symptoms including diarrhea, rectal bleeding, abdominal pain, fatigue, growth failure, and delayed puberty present unique psychosocial challenges (1). This is particularly true for adolescents, who make up the majority of diagnosed pediatric cases (2) and are faced with learning to manage a chronic condition that is difficult to discuss with others while attempting to maintain a typical adolescent lifestyle and negotiate normal developmental issues. Treatment for IBD is complex with regard to the number of medications/supplements and their varying dosing regimens. The episodic, variable, and unpredictable disease exacerbations often result in at least temporarily changing drug therapies. Moreover, this unpredictable natural disease course can be discouraging to patients and may set the stage for poor self-management and nonadherence. Although the research on self-management in pediatric IBD is still relatively new, there is increasing evidence of the magnitude and scope of the problem as well as how best to promote self-management in clinical practice. A summary of this evidence and recommendations for clinicians at this juncture can facilitate and guide research and clinical practice in the most prudent directions.

The objective of this clinical report is to provide a review of self-management and adherence issues in pediatric IBD, factors associated with self-management, and approaches to the measurement of self-management. Additionally, this report provides empirically supported recommendations for clinicians regarding assessment and treatment approaches to promote self-management.

DEFINITIONS AND CONCEPTUALIZATION

The terms ''self-management,'' ''adherence,'' and ''compliance'' have often been used interchangeably; however, there are important conceptual differences that have implications for both clinical intervention and clinical research. ''Compliance'' has been used commonly, although it has fallen out of favor because of the connotation of patient obedience and blame associated with the term (ie, patients do or do not follow directions). The term ''adherence'' has become more widely used and accepted in the last several years because it suggests a more positive interpretation of patient behavior, reflects patient–clinician concordance in treatment planning, and implies a continuum of patient behavior related to medication taking or other treatments. Adherence is defined as ''the extent to which a person's behavior (in terms of taking

medications, following diets, or executing lifestyle changes) coincides with medical or health advice'' (3). More important adherence is a quantification of self-management behaviors and thus conceptualized as an outcome or mediator of disease outcomes. The term ''self-management'' is defined as ''the interaction of health behaviors and related processes that patients and families engage in to care for a chronic disease'' (4). Thus, self-management behavior results in the extent to which patients are adherent, and this may affect disease outcomes. The term ''self-management support'' focuses on the clinician's role in patient self-management and refers to ''the care and encouragement to people with chronic conditions and their families to help them understand their central role in managing their illness, make informed decisions about care, and engage in healthy behaviors'' (5).

Although this report focuses on self-management in IBD, we discuss adherence considerations and research data throughout because this is the most proximal and most often used outcome of self-management behavior. Moreover, adherence/nonadherence is an issue of primary clinical concern for practitioners. To provide guidance for clinical practice and research, we provide an overview of factors associated with self-management, review strategies for assessing self-management in research and clinical practice contexts, and discuss opportunities for integrating self-management into clinical care. We conclude with a discussion of future directions for self-management research and practice.

FACTORS ASSOCIATED WITH SELF-MANAGEMENT BEHAVIOR

The majority of research examining factors associated with self-management behavior has focused on correlates or predictors of oral medication adherence in pediatric IBD. Studies have generally grouped youth with Crohn disease (CD) and ulcerative colitis (UC) together and have examined cross-sectional rather than longitudinal associations in combined samples of children and adolescents. A number of factors have been examined, including sociodemographic factors, disease or disease regimen factors, individual factors, family factors, social factors, and health care system factors.

Sociodemographic Factors

Among pediatric patients with IBD, sociodemographic factors including age, sex, and ethnicity have not been associated with an increased risk of nonadherence to medication regimen; however, among adults with IBD, full-time employment status, higher education level, being single, male sex, and African American ethnicity have each been associated with medication nonadherence (6–11).

Disease or Disease Regimen Factors

Aspects of IBD and the disease management regimen may adversely influence adherence. Among preadolescents and adolescents with IBD, regimen factors associated with nonadherence include perceived adverse effects associated with medication use (12,13), greater perceived regimen complexity (13), and objective reports of regimen complexity (eg, multiple-daily dosing versus once-daily dosing (12,14)). Other patient-reported barriers to adherence related to the disease management regimen include large pill size, difficulty swallowing the medication, and unpleasant taste of the pill (13,14).

Disease activity has been the disease-related factor most often studied in relation to nonadherence in pediatric IBD. Although some studies have found higher rates of medication nonadherence among individuals with less disease activity (15), other studies have found an opposite pattern of association. Specifically, Greenley et al (12) found that youth with any disease activity were 3.5 times more likely to be nonadherent. Similarly, not feeling well was reported as a barrier to adherence in 1 recent study (16). Additionally, Schurman et al (13) found that high disease activity was associated with volitional nonadherence, but that disease activity was unrelated to accidental nonadherence.

Individual Factors

Developmental, cognitive, and psychological factors may either facilitate or serve as barriers to adherence. Regarding developmental factors, adolescence is regarded universally as a time of poor adherence across chronic medical conditions (17). The developmental changes of adolescence include a greater desire for autonomy, more time spent outside the home, and an increased need to ''fit in'' with peers (18). These normative changes are at odds with completion of disease management tasks and the need to incorporate management of a chronic disease into one's social routine. In support of this, Hommel and Baldassano as well as Ingerski and colleagues have reported that interference with activities and not being home are barriers to adherence among adolescents with IBD (14,16).

Cognitive factors such as knowledge, beliefs, and planning/organizational skills also influence adherence. Knowledge of one's disease and regimen is a necessary but not sufficient condition for adherence, because youth and families must understand what the treatment regimen is and how to carry out illness self-management tasks before they are able to follow the regimen (19). Recently, less sophisticated knowledge related to supplements used in IBD was associated with poorer adherence to supplements in a preadolescent and adolescent IBD sample (20). Additionally, beliefs of lack of medication efficacy or that the medication is unnecessary have been documented as barriers to adherence in pediatric IBD (12,16). Finally, planning and organizational difficulties have been identified as barriers to adherence. Specifically, reports of forgetting to take medication, failing to plan ahead, and forgetting to get the prescription filled on time have been reported as adherence barriers in pediatric IBD (14,16).

Patient psychological functioning may also serve as a barrier to adherence. Depressive symptoms have been associated with nonadherence in youth with IBD (21). In addition, child oppositional behavior has been reported as a barrier to adherence in teens with IBD (14,16). Finally, Mackner and Crandall documented a relation between avoidant coping strategies and nonadherence in children with IBD (22).

Family Factors

Family factors influence adherence among children and adolescents with IBD. Mackner and Crandall documented a relation between higher levels of family dysfunction and nonadherence in pediatric IBD (22). Similarly, Hommel and Baldassano (14) noted that family or parent–child conflict about taking medications is an adherence barrier. In addition, data suggest that both high adolescent and parent involvement in disease management are associated with better adherence (23,24).

Social Factors

Among adolescents with IBD, social factors such as a wish for friends not to know about the patient's IBD or a refusal to take medication in public may be barriers to adherence (13). Similarly, a

belief that medication interferes with activities is another potential barrier to adherence (13,14,16).

Health Care System Factors

In a recent study, adherence to oral thiopurine medications was significantly higher in the 3 days before, the day of, and the 3 days after a pediatric gastrointestinal specialty appointment among youth ages 11 to 18 years with IBD, indicating that more frequent provider contact may have enhanced accountability and encouraged improved adherence, at least in the short term (25).

Other health professional relationship factors have been associated with adherence in multiple pediatric populations (26,27) and among adults with IBD (28). Specifically, among adults with IBD, low trust in physician (29), working with the treating physician for <1 year (30), and discordance between patient and physician on perceptions of patient health status (30) have been associated with nonadherence. Additionally, pediatric patients who are more satisfied with their medical care are more likely to follow treatment recommendations (26). Similarly, provider verbal support, continued contact with the same provider, perceptions of provider empathy and support, and trust in one's provider have also been associated with higher adherence in pediatric samples (7,26,27). Although such factors are likely to influence adherence in pediatric IBD, they have yet to be systematically examined.

NONADHERENCE: SCOPE OF THE PROBLEM AND RELATION TO OUTCOMES

Prevalence and Frequency of Nonadherence

All of the aforementioned factors influence self-management behavior and the extent to which an individual adheres to the prescribed treatment. Nonadherence to medical treatment is an important but underrecognized clinical issue affecting the care and well-being of children and adolescents with pediatric IBD. Although overall adherence to the IBD treatment regimen is suboptimal, adherence varies widely based on the type of medication (eg, specific medication and prescription vs nonprescription), specific adherence behavior examined (eg, oral medication vs dietary modifications), and how adherence is measured (eg, patient report vs pill count). In general, adherence to prescription medications is >20% higher than adherence to over-the-counter medications such as multivitamins, calcium, and iron (24). Among prescription medications, nonadherence significantly differs between immunomodulators and aminosalicylates. Nonadherence prevalence for 5-aminosalicylate (5-ASA) is as high as 88%, whereas 6-mercaptopurine (MP)/azathioprine (AZA) nonadherence prevalence is 64% (31). Higher rates of nonadherence to 5-ASA are not surprising because adolescents with IBD are much more likely to experience barriers to adherence when treatment involves more than once-daily medication administration (12).

Diet is another important component of IBD management (32); however, adherence to dietary recommendations has been understudied because of the absence of standard recommendations for dietary management of IBD. In addition, variability across patients regarding dietary contributors to IBD symptomatology and limited methods of assessing adherence to dietary recommendations (ie, self-report) make it difficult to gauge how common dietary nonadherence is among the broader pediatric IBD population. In one of the few studies examining dietary adherence in IBD, 25% of adolescents prescribed gastrostomy tube feedings were nonadherent to treatment (33); however, given the small sample of this study, further examination of dietary adherence in IBD is needed.

Relation of Nonadherence to Disease and Psychosocial Outcomes

Nonadherence is a concern for several reasons. Numerous studies have reported an association between nonadherence to IBD treatment and negative health and psychosocial outcomes. Not surprisingly, patients who are nonadherent are more likely to have greater disease severity (21,23,24), potentially necessitating the need for more aggressive medical treatment, such as increased corticosteroid use or surgery. Patients with IBD who are nonadherent to treatment also have increased health care costs (34) and have a higher risk for disease recurrence (35). In addition to these medical consequences, nonadherence is linked to poorer psychosocial functioning. Specifically, children and adolescents who are less adherent to their prescribed treatment regimen are more likely to experience poorer quality of life (36) and greater anxiety/depressive symptoms (21). Given the severe and potentially irreversible nature of these medical and psychosocial consequences of nonadherence, early intervention with patients who are nonadherent is important. Identifying nonadherence through use of ≥1 assessment methods is an important first step in improving self-management.

MEASUREMENT OF ADHERENCE

There is no criterion standard of adherence assessment. Each method has strengths and limitations (Table 1). A multimethod adherence assessment approach that draws on the strengths of different assessment methods is recommended.

Patient/Parent Report of Adherence

Patients/parents are ideally suited to report adherence because they are responsible for following the treatment regimen on a daily basis. They can provide information regarding barriers to adherence as well as adherence to other aspects of the treatment regimen, such as dietary habits, that cannot be measured using other assessment methods. This information may inform clinical decision making and the delivery of targeted interventions. Accuracy is a major concern with patient/parent report because poor memory of missed doses and the desire to be viewed favorably by others (eg, social desirability bias) lead to inflated estimates. For example, nonadherence prevalence of patient/parent report is 10% for 6-MP/azathioprine (AZA) and 2% for 5-ASA; however, pill count estimates suggest much higher estimates of nonadherence (64% for 6-MP/AZA and 88% for 5-ASA) (23,31).

Accuracy of patient/parent report can be improved by refining how adherence is assessed. How providers ask about nonadherence affects patient/parent responses. For example, a question such as ''You're taking all of your medicine, correct?'' is likely to result in higher patient/parent report of adherence than ''How many doses of your 6-MP did you miss over the past week?'' Brief structured interviews/questionnaires (eg, Medication Adherence Measure (37), Morisky Medication Adherence Scale (38,39)) can also improve the accuracy of patient/parent report and have been previously used in patients with IBD (16,24,31,40).

Clinician Estimate

In general, clinicians are extremely good at identifying adherent patients, but they are much less accurate at identifying nonadherence and their estimates of adherence are not associated with health outcome (41–43). Clinician estimates are influenced by unreliable factors such as patient/parent report (which

TABLE 1. Overview of strengths and limitations of adherence assessment approaches

Assessment method	Strengths	Limitations
Patient and/or parent report or interview, diet records or recall	Easy, inexpensive to obtain, provides patient and/or parent perceptions of adherence behavior and barriers to adherence	Can overestimate adherence, subject to patient recall bias and social desirability
Provider estimates	Easy, inexpensive to obtain	Poor reliability and validity, often based on disease status rather than perceived adherence behavior
Direct observation	Accurate, only method that can confirm medication consumption frequency	Resource intensive, limited feasibility in routine clinical care and research
Pill counts	Easy, inexpensive to obtain, fairly accurate	Can be cumbersome to collect and calculate, requires patients bringing medications to appointments, can be manipulated positively or negatively
Pharmacy record data	Provides objective data on refill behavior, can easily assess multiple medications	Assesses refill behavior not consumption, may be difficult or costly to obtain
Electronic monitoring	Wealth of data, objective, fairly accurate	Expensive, may not be feasible for patients with multiple medications, may not be acceptable to patients, equipment may malfunction
Biological assays	Confirms consumption but not timing or amount of doses	Expensive, subject to pharmacokinetic variation and metabolism, can be manipulated by recent dosing depending on medication, not available for all medications

overestimates adherence), the patient's current health status (which is influenced by other factors such as subtherapeutic dosing, illness, pharmacokinetic variability), and their knowledge of the patient's history of adherence/nonadherence (eg, ''this patient is typically adherent/nonadherent''). As a result of these limitations, clinician's estimate is not considered a reliable and valid method of assessing adherence (44).

Direct Observation

Direct observation can confirm ingestion of medication but is time and labor intensive because another individual (eg, reliable family member, inpatient hospital staff) must be present to observe each medication administration. Although accurate, the resource-intensive nature of this approach limits its feasibility in clinical practice and research.

Pill Count

Pill counts compute an adherence rate based on the number of pills a patient has initially, the number of pills the patient is expected to have consumed during a predetermined period of time, and the number of pills remaining at the end of this time. This low-cost method is more accurate than patient/parent report (31), but can be cumbersome and time consuming, particularly if patients have $\geq$1 medication. Missing data are possible because 2 data points (eg, number of pills patient has initially, number of pills remaining) are needed to compute adherence and patients may forget to bring in their pill bottles. Pill counts can also be positively or negatively manipulated. Medication can be discarded or lost. Families may combine old and new medication bottles, resulting in underestimates of adherence or unusual pill count data (ie, increasing rather than decreasing number of pills) that are difficult to interpret without complementary data (ie, pharmacy refill data).

Pharmacy Refill

Pharmacy refill data do not estimate adherence, but rather provide data on refill behaviors that are believed to correspond to how well a patient takes his or her medicine. There are no data examining the validity of pharmacy refill data as a measure of adherence in pediatric IBD. A study comparing pharmacy refill data to other objective methods of assessing adherence (eg, pill count, electronic monitoring) in IBD is needed. This approach may be less desirable when working with patients who receive their prescription in multimonth supplies, who have their medication on an automatic refill schedule, or who often switch between multiple pharmacies. Privacy regulations to protect patient health data and fees that some pharmacies are now charging before releasing their records may also make use of refill records unfeasible.

Electronic Monitoring

Electronic monitors record the date and time that medication was accessed from the container and compare this to the prescribed regimen to produce an overall adherence estimate (for a review of existing technologies, see Ingerski et al (45)). Electronic monitors provide valuable information on medication-taking patterns (eg, patient is inconsistent with evening doses, takes weekend medications much later than prescribed) that are not otherwise available using other assessment methods. This information may guide the delivery of targeted intervention efforts. Electronic monitors have several limitations. In addition to specialized equipment and software, each electronic monitor may cost several hundred dollars. Monitors tend to be bulky and difficult to transport. They are not compatible with all forms of medication (eg, liquid medicine) and they may interfere with present adherence routines (eg, patients used to using a pill box may experience declines in adherence when asked to switch to an electronic pill bottle). Monitors can also malfunction, get damaged/lost, or be used incorrectly, resulting in incorrect estimates or complete data loss (45).

Bioassay Metabolite Monitoring

Bioassays can indicate whether medication has been recently taken and can assist in treatment decision making to ensure patients stay within a specified therapeutic range; however, not all medications have an associated bioassay available or established

therapeutic levels to guide interpretation of data. Pharmacokinetic variations in an individual's drug absorption, metabolism, and excretion (46) as well as the patient's recent medication-taking behavior may influence results. Thus, patients who are generally nonadherent but tend to take their medicine just before a medical appointment (ie, white coat compliance (47)) appear to be more adherent than they truly are; however, bioassays are helpful in identifying extreme cases of nonadherence (eg, patient has little-to-no medication in their blood).

PRACTICE RECOMMENDATIONS FOR CLINICIANS

Routine Adherence Screening

Adherence assessment, via reliable assessment tools (eg, pill count, electronic monitoring, pharmacy refill data), should be implemented as part of pediatric IBD standard clinical care (Table 2). The benefits of routine assessment are multifold. Routine assessment improves early detection of nonadherence and, thus, poor self-management behaviors. In turn, clinical care can focus on primary prevention (clinically significant nonadherence is not present) rather than secondary (clinically significant nonadherence is identified early) or tertiary prevention (an ongoing pattern of clinically significant nonadherence and poor self-management) (48). Early detection can lead to interventions to improve adherence. Because nonadherence is associated with increased disease severity (21,23,24,49), early detection and intervention of nonadherence may prevent declines in the health and well-being of young patients with IBD. Routine assessment of adherence can also be used to identify patients and families in need of clinical intervention aimed at improving self-management behavior. Because the level and type of clinical intervention can become more complex and time-consuming as nonadherence worsens, proactive assessment can drastically cut down on the time spent addressing issues related to nonadherence during clinical visits.

Promotion of Self-Management

The aforementioned assessment tools are powerful agents of change in the clinical care of youth with IBD. They can guide treatment planning and be used to determine the type and level of intervention needed to improve adherence and self-management behaviors. A recent meta-analysis of adherence-promoting interventions revealed that behavioral and multicomponent interventions show the greatest promise for improving adherence among youth with chronic medical conditions (50). Behavioral interventions emphasize behavior change to improve self-management behaviors and include goal setting, reward systems, and adherence monitoring, among other techniques. Multicomponent interventions combine various treatment approaches, including behavioral, educational, organizational, and family-centered components. Among youth with IBD, emerging evidence suggests that multicomponent interventions tailored to the unique adherence needs of adolescents with IBD may result in substantial improvements in oral medication adherence (51). Across adherence-promoting interventions, however, improvements have been shown to diminish over time (50). This suggests that improvements in adherence and self-management behaviors are most likely to be maintained with ongoing intermittent intervention. Adherence intervention needs to become part of a patient's ongoing clinical care, rather than a 1-time treatment approach because this is mostly likely to capture adherence barriers as they occur in closer proximity to real time.

For example, forgetfulness has been identified as a key barrier to adherence among youth with chronic medical conditions, including IBD (14,16). Targeting this barrier may include the following treatment components: increased monitoring by the youth and caregivers (eg, keeping daily logs on the refrigerator and checking off when a particular medication has been taken, checking pill containers); auditory/visual reminders (eg, setting a cell phone/watch alarm that goes off at the time medication is supposed to be taken, making visual reminder signs); and behavior contracting (eg,

TABLE 2. Recommendations for clinical providers

Who
Seek out multiple reporters of adherence (eg, patient, caregiver)
Involve caregivers in adherence-promoting interventions; improves generalizability to home environment
When
Use routine screening of adherence as part of standard of care
Maintain ongoing monitoring of adherence behaviors
What
Target multiple adherence and self-management behaviors (eg, medication taking, exercise, diet, and clinic attendance)
Identify barriers to adherence and self-management. For example:
Patient/family-specific factors (eg, adolescent age, knowledge of disease and treatment, psychological functioning, family conflict, parent involvement)
Disease-specific factors (eg, disease activity)
Treatment-specific factors (eg, cost, complexity, perceived adverse effects)
How
Use at least 2 separate measures of adherence; 1 objective measure is recommended (eg, drug assays, pill counts, pharmacy records)
Give patients feedback on adherence data, and engage them in change and intervention
Adherence-promoting intervention should be individually tailored to each patient's needs
Behavioral and multicomponent interventions show greatest promise for improving adherence. For example:
Setting goals around adherence and self-management
Developing behavior contracts, reward systems
Adherence monitoring
Consider clinic setting as an excellent teaching and learning environment (eg, role-play and behavioral rehearsal of disease management tasks)
Use multimodal approach to education (eg, supplement verbal instructions with written treatment plans and instructions)
Consider referral to other subspecialties, including psychology and psychiatry, social work, patient financial assistance

youth earns points, incentives, or privileges for remembering to take medication a specified number of times each week). Sometimes patient adherence is low because of pill-swallowing difficulties or palatability/taste issues (52). In such cases, adherence can be targeted by modeling and teaching appropriate pill-swallowing methods or by modifying how pills are taken (eg, eating something immediately before/after, putting the pill in ice cream, applesauce, or pudding).

Clinic-Based Intervention

Adherence interventions are not routinely integrated into patients' usual care, and clinic-based interventions are lacking (53). Thus, it is unclear whether empirically supported treatments for nonadherence can be implemented in a medical clinic setting. It is also unclear whether components of these interventions can be feasibly implemented by medical providers in clinical settings. Regardless, 1 size does not fit all in adherence-promoting intervention, what works for 1 patient may be unsuccessful for another patient. Clinicians are encouraged to individualize an intervention to the specific adherence needs and barriers experienced by a particular patient because there is likely to be great variability across patients. To further improve self-management among young patients with IBD, clinicians should provide written treatment plans and instructions to families to reinforce information given verbally. In-clinic modeling, rehearsal, and practice of various disease-management tasks (eg, taking medication, administering injections, filling a pill box, selecting healthy food choices) can also be helpful with young patients (54). Clinicians should also consider including parents/caregivers in self-management interventions because they often manage the patient's illness and treatment on a daily basis.

Referral for Treatment

In some cases, a referral to another provider with expertise in behavioral health interventions may be warranted. Many youth with IBD experience internalizing (eg, anxiety, depression) or externalizing (eg, acting out, oppositional behaviors) difficulties (55) that may affect their self-management behavior. Family stressors or parent mental health may also be comorbid with nonadherence, and these issues may cause, exacerbate, or maintain poor adherence. Under such circumstances, referral for behavioral health services and/or additional support services for the patient, parent, and/or family may be necessary before or during efforts to address poor self-management.

FUTURE DIRECTIONS

Broadening Self-Management Focus

Given the long-term complexities of chronic conditions, medical management is viewed by some as only 1 aspect of a broader conceptualization of self-management. Lorig and Holman (56) conceptualize self-management as maintaining a wellness perspective in the context of a chronic condition, and they describe 3 components: medical management, social/role management to create new behaviors or life roles to adapt to a chronic condition, and emotional management of the psychosocial sequelae of having a chronic condition. In contrast to acute illnesses, chronic conditions are more likely to evolve over time, have multiple etiological factors that may also change over time, have a waxing and waning course, uncertain prognosis, and require changing management over time (57). They often result in continuous medication use, behavior change, changed social circumstances, and emotional distress (57).

This broader view of self-management fits well with present perspectives on defining the concept of ''health.'' Previous definitions of health were developed when acute diseases were more common than chronic conditions (58). A recent multidisciplinary international panel recommended a conceptualization of health that focuses on resilience, or maintaining and restoring ''one's integrity, equilibrium, and sense of well-being'' (58). Specifically, they defined health as ''the ability to adapt and to self-manage'' in physical, mental, and social domains. The focus on wellness and the 3 domains maps well onto the conceptualization of self-management described by Lorig and Holman (56). Given the complexities of chronic conditions such as IBD and the evolving definitions of health and self-management, an important future direction is to broaden our self-management focus in pediatric IBD.

Measurement Considerations

As our conceptualization of self-management broadens, we must also strive toward improving our assessment and measurement of self-management behaviors. As Table 1 illustrates, there are a number of options for measurement of adherence; however, none are perfect or 100% accurate and reliable. Much work is needed, particularly in the areas of electronic monitoring and algorithmic assessment approaches. Many electronic monitoring devices have been developed, but they have fallen short of providing a user-friendly product for patients with IBD. One of the more common problems with these is many of these devices do not accommodate large pills well. Other persistent issues involve reliability and data capture and transfer (45). In addition, the testing and validation of algorithms using combined adherence assessment methodology are necessary. There has also been little done to standardize approaches to combining adherence measures reliably. For example, an algorithm using self-report/parent report, pill counts, and 6-thioguanine nucleotide (6-TGN)/6-methylmercaptopurine nucleotide (6-MMPN) bioassay data would be feasible and useful in the IBD population. Finally, measurement needs to focus more on self-management behavior itself rather than solely on adherence. It will be important to clearly define the most critical self-management behaviors and develop measurement tools that are clinically useful and feasible. This will be challenging, but the utility of such tools may prove equally or more beneficial than adherence assessments because they may define a broader range of behavior that affects health and well-being.

Clinical Effectiveness, Comparative Effectiveness, and Quality Improvement

Comparative effectiveness research that tests the relative effect of efficacious interventions for improving self-management in IBD will allow us to identify the most beneficial components. Similar to this, interventions themselves will need to be optimized by determining the most effective components of treatment and designing programs that incorporate only the critical pieces of treatment protocols. In addition, a disadvantage of the relatively sterile environment in which well-controlled behavioral research is conducted is that there may be limited clinical use of the intervention. Psychological and disease comorbidities that introduce complexity to behavioral functioning and prescribed treatment regimens may present unforeseen difficulties to the success of efficacious interventions. Thus, it will be imperative that the clinical effectiveness of efficacious self-management interventions be carefully evaluated via testing with patients presenting with complex medical conditions and behavioral comorbidities. Finally, many self-management and self-management support interventions can be delivered in clinics.

Challenges exist with this type of approach, however, including logistical processes, adoption of new practices, and clinic flow issues. A quality improvement approach is ideal for identifying practice-level challenges and developing methods to overcome them, determining what existing local conditions will hinder or facilitate certain interventions, and establishing a culture of continuous improvement in self-management provision from both the clinician and patient/family perspectives. In conclusion, a well-planned and implemented approach that incorporates comparative effectiveness, clinical effectiveness, and quality improvement research methodologies will significantly advance and accelerate our knowledge and provision of self-management interventions in the pediatric IBD population.

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