

Practice survey: adherence monitoring and intervention in pediatric gastroenterology and hepatology

Michele H Maddux^{1,2}
Shawna Ricks²
Julie A Bass²
James F Daniel²
Ellen Carpenter²
Kimberely Radford²

¹Division of Developmental and Behavioral Sciences, Children's Mercy-Kansas City, Kansas City, MO, USA; ²Division of Gastroenterology, Children's Mercy-Kansas City, Kansas City, MO, USA

Purpose: Despite significant medication nonadherence rates among youth with pediatric gastroenterology and hepatology disorders, little is known about current adherence practices in pediatric gastroenterology care. This study summarizes current practices surrounding adherence monitoring and intervention in pediatric gastrointestinal (GI) and hepatologic care in the USA.

Participants and methods: One hundred and fifty-four pediatric GI providers completed an online survey designed to examine current practices surrounding adherence monitoring and intervention, specific strategies used to monitor and treat poor adherence, and the barriers currently experienced in relation to adherence monitoring and intervention.

Results: Practices varied greatly in terms of when and how patient adherence is monitored and by whom; however, physicians and nursing professionals take primary responsibility for adherence monitoring. Approximately 25% utilize screeners to assess adherence, and most participants use patient and caregiver reports as a primary measure of adherence. Most participants rated their level of adherence monitoring and intervention as fair to poor. While most participants perceive adherence monitoring to be very important in clinical practice, only 20.8% perceive being able to significantly modify patient adherence.

Conclusion: There exists great variability in adherence monitoring and intervention practices across pediatric GI providers. Greater understanding of current adherence practices can inform future clinical efforts.

Keywords: adherence, screening, clinical practice, intervention, compliance

Introduction

Poor adherence to treatment regimens, which refers to the extent to which a person's behavior coincides with medical advice, is a significant problem across pediatric conditions. In fact, poor adherence has been deemed to be the primary cause of treatment failure in pediatrics.¹ It carries considerable implications for morbidity and mortality, cost-effectiveness of medical care, and disease management decisions by health care providers.² Poor adherence among chronically ill youth is associated with significantly poorer quality of life, impairments in psychosocial and physical functioning, greater absenteeism from daily activities, and greater health care utilization.^{2,3} Across pediatric conditions, extant literature suggests that ~50% of children and 65%–75% of adolescents are nonadherent to prescribed medical regimens.^{3–5}

In pediatric gastroenterology and hepatology, most adherence research has focused on pediatric inflammatory bowel disease (IBD) and pediatric liver disease. Management of these medical conditions can be time consuming and complex, as treatment regimens can include a combination of oral medication, IV medication, as well

Correspondence: Michele H Maddux
Division of Developmental and Behavioral Sciences, Division of Gastroenterology, Children's Mercy-Kansas City, 2401 Gillham Road, Kansas City, MO 64109, USA
Tel +1 816 234 3862
Fax +1 816 302 9898
Email mhmaddux@cmh.edu

dietary and lifestyle modifications (eg, restricted physical activity). Empirical research in pediatric IBD has demonstrated nonadherence prevalence as high as 64%–88%.⁶ The most commonly identified barriers to adherence in pediatric IBD include forgetting, interference with other activities, difficulty swallowing pills, and not being at home.⁷ Some families also intentionally do not follow the IBD treatment regimen, particularly in the absence of disease symptoms, to simplify the treatment regimen, and/or to alleviate side effects.⁸ Yet, poor adherence to oral medication in IBD has been linked to a fivefold increased risk of relapse,⁹ a 12.5% increase in annual health care costs,¹⁰ and greater health care use (ie, hospitalizations, emergency department visits, outpatient visits³). Among pediatric liver transplant recipients, nonadherence rates have been found as high as 42%–50% within 5 years following transplant.¹¹ Poor adherence to oral medication has also been linked to significantly greater graft loss in adolescent liver transplant recipients.¹² These nonadherence rates are alarming, especially considering that even minor deviations from a dosing schedule can be associated with negative health outcomes. Also, nonadherence in the US costs between \$100 and \$300 billion yearly, which amounts to 3%–10% of total US health care costs.^{4,13}

In light of high nonadherence rates in pediatric gastroenterology and hepatology and the impact on patient outcomes, it is imperative to monitor adherence as part of standard clinical care and provide targeted intervention. Such a proactive approach is likely to identify adherence difficulties early on, thereby ensuring that poor adherence does not place youth at increased risk of morbidity and mortality. In spite of the aforementioned evidence of prevalent nonadherence, little is currently known about clinical practices around adherence to prescribed treatment regimens in pediatric gastroenterology and hepatology. This project is aimed at characterizing current practices surrounding adherence monitoring and intervention in pediatric gastrointestinal (GI) and hepatologic care in the USA.

Participants and methods

Ethical considerations

All study procedures were approved by the Institutional Review Board at Children's Mercy-Kansas City. Data were collected anonymously, and consent to participate was implied by voluntary participation of the study survey.

Participants and procedures

Providers were identified from several sources: 1) the North American Society for Pediatric Gastroenterology,

Hepatology, and Nutrition, 2) the Association of Pediatric Gastroenterology and Nutrition Nurses, and 3) an internet search of pediatric GI/hepatology providers across the USA. These sources included private practice providers as well as those within hospitals or academic medical centers. Inclusion criteria included specialty medical care in the field of pediatric gastroenterology and/or hepatology, and English fluency.

Once participants were identified, study data were collected and managed using Research Electronic Data Capture (REDCap) electronic data capture tools hosted by the study site.¹⁴ REDCap is a secure, web-based application designed to support data capture for research studies, providing 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources. Participants were sent a REDCap-generated email link to the survey with an invitation to participate and instructions for completing the survey. Two waves of reminder emails automatically generated within REDCap were sent to all participants 2- and 4-weeks after the initial email invitation was sent.

Measure

A 36-item survey was developed by authors of this study. The survey was designed to examine adherence-focused clinical practices including but not limited to, the involvement of various disciplines (eg, physician assistant, nurses, social workers, psychologists) in adherence monitoring and intervention, current practices surrounding adherence monitoring and intervention, specific strategies used to monitor and treat poor adherence, and the barriers currently experienced in relation to adherence monitoring and intervention. The definition of adherence according to the World Health Organization was included; "Adherence is defined as the extent to which a person's behavior coincides with medical advice. This might include taking medication, following diets, or implementing lifestyle changes."¹ Content was developed on the basis of extant literature that outlined best practice clinical guidelines for adherence monitoring and intervention, and common barriers to implementation. The questionnaire was reviewed for content and clinical utility by a group of pediatric providers (ie, pediatric gastroenterologist, advance practice nurse) who provided specialty medical care in pediatric gastroenterology and hepatology, and were programmatically involved in adherence-focused clinical care among this pediatric patient population.

Statistical analyses

Frequency data was calculated as percentages to summarize feedback obtained across each survey item. Descriptive statistics, including means and standard deviations, were calculated for survey items rated on a Likert scale. Group differences were examined via analysis of variance tests. Analyses were conducted in SPSS 23.0 (SPSS Inc., Chicago, IL, USA).

Results

Participant and practice characteristics

A total of 154 professionals, representing 83 distinct practices/institutions, completed the survey. Most participants were physicians (49.4%) with >15 years of practice (40.9%), practicing within children's hospital settings, either free-standing or housed within a larger hospital (91.5%; Table 1). Most participants practiced in a setting with >500 patients (79.9%), with various provider types other than physicians

Table 1 Participant characteristics and practice settings (n=154)

Characteristic	% (n)
Gender (female)	63.2 (96)
Number of years in clinical practice	
≤5 years	25.3 (39)
6–15 years	33.8 (52)
>15 years	40.9 (63)
Geographic location of practice	
West	16.9 (26)
Southwest	5.8 (9)
Rocky Mountains/plains	5.2 (8)
Midwest	35.1 (54)
Southeast	15.6 (24)
Middle Atlantic	14.3 (22)
New England	7.1 (11)
Practice setting	
Children's hospital, free-standing	51.9 (80)
Children's hospital, located within a larger hospital	39.6 (61)
Private practice	6.5 (10)
Other (eg, free-standing outpatient clinic for children's specialties, university hospital department of psychiatry)	1.9 (3)
Profession	
Physician	49.4 (76)
Physician assistant	0.0 (0)
Fellow	2.6 (4)
Nurse	5.2 (8)
Nurse practitioner	20.1 (31)
Psychologist	18.2 (28)
Social worker	3.2 (5)
Nutritionist/dietician	0.0 (0)
Program coordinator	1.3 (2)
Medical assistant	0.0 (0)
Other	0.0 (0)

(Continued)

Table 1 (Continued)

Characteristic	% (n)
Patient population age range	
Children (0–12 years)	99.4 (153)
Adolescents (13–18 years)	97.4 (150)
Young adults (19–25 years)	65.6 (101)
Adults (26+ years)	3.2 (5)
Size of gastroenterology/hepatology patient population at practice	
0–100	4.5 (7)
101–200	1.9 (3)
201–300	5.2 (8)
301–400	3.2 (5)
401–500	5.2 (8)
501+	79.9 (123)
Health conditions treated	
Inflammatory bowel disease	77.9 (120)
Celiac disease	75.3 (116)
Functional abdominal pain	81.8 (126)
Eosinophilic esophagitis	76.0 (117)
Eosinophilic gastroenteritis	62.3 (96)
Motility disorders	59.1 (91)
Gastroesophageal reflux	79.9 (123)
Functional dyspepsia	74.0 (114)
Short bowel/short gut syndrome	61.7 (95)
Irritable bowel syndrome	79.2 (122)
Familial adenomatous polyposis/polyposis syndromes	51.3 (79)
Colorectal cancer	14.3 (22)
Liver disease	63.0 (97)
Liver transplant	32.5 (50)
Constipation	83.8 (129)
Encopresis	79.2 (122)
Failure to thrive	77.9 (120)
Cyclic vomiting	72.7 (112)
Other (eg, pancreatic diseases, feeding disorders, rumination disorder)	15.6 (24)
Providers seeing patients in practice	
Physician	95.5 (147)
Physician assistant	11.0 (17)
Fellow	47.4 (73)
Nurse	53.9 (83)
Nurse practitioner	74.0 (114)
Psychologist	45.5 (70)
Social worker	53.9 (83)
Nutritionist/dietician	74.7 (115)
Program coordinator	12.3 (19)
Medical assistant	33.8 (52)
Other (eg, fitness trainer, occupational and speech therapist, surgeon, pharmacist)	9.1 (14)

seeing patients (eg, nurse practitioner, nutritionist/dietician, psychologist, social worker).

Adherence monitoring practices

Most participants (74.7%) reported monitoring patient adherence as part of standard clinical care, with approximately half of this subset monitoring adherence with all

patients (Table 2). Among this subset, monitoring patient adherence is largely the responsibility of the physician (75.3%) or nurse practitioner (47.4%), and this is largely done at every patient visit (70.1%). Approximately one-fourth of

Table 2 Adherence monitoring practices (n=154)

Practice characteristic	% (n)
Monitoring as standard clinical care (% yes)	74.7 (115)
Patient criteria for monitoring	
All patients	55.8 (86)
Subset (eg, patients with IBD, celiac disease, or liver transplant, patients with adherence difficulties, patients on medication for which drug levels are monitored)	44.2 (68)
Tasked with monitoring patient adherence	
Physician	75.3 (116)
Physician assistant	8.4 (13)
Fellow	26.0 (40)
Nurse	42.2 (65)
Nurse practitioner	47.4 (73)
Psychologist	19.5 (30)
Social worker	12.3 (19)
Nutritionist/dietician	11.0 (17)
Program coordinator	3.9 (6)
Medical assistant	5.2 (8)
Other (eg, pharmacist, research coordinator)	4.5 (7)
No one is responsible for monitoring adherence	12.3 (19)
Monitoring frequency	
Once yearly	3.2 (5)
Twice yearly	1.3 (2)
At every patient visit	70.1 (108)
Depends on the patient	20.8 (32)
Never	7.1 (11)
Other	0.6 (1)
Use of screening measures (% yes)	24.7 (38)
Screening measure type	
MMAS	12.3 (19)
MAM	0.6 (1)
BMQ	4.5 (7)
MARS	1.3 (2)
AMBS/PMBS	0.6 (1)
Other (eg, TRAQ, measure developed internally)	7.8 (12)
Screening measure frequency	
Once yearly	1.3 (2)
Twice yearly	0.0 (0)
At every patient visit	21.4 (33)
Depends on the patient	2.6 (4)
Never	0.0 (0)
Other	1.3 (2)
Screening measure data usage	
Reviewed with patient and family	18.8 (29)
Reviewed by medical team	17.5 (27)
Used to make referrals for targeted adherence intervention	5.2 (8)
Used to develop action plan to improve adherence	12.3 (19)
Used to make changes to patient's treatment regimen	13.0 (20)
Research	5.2 (8)
Quality improvement	10.4 (16)
Data not currently being used	0.6 (1)

(Continued)

Table 2 (Continued)

Practice characteristic	% (n)
Additional monitoring/measurement methods	
Patient self-report	87.7 (135)
Parent/caregiver report	78.6 (121)
Provider estimates	20.1 (31)
Pharmacy records	31.2 (48)
Pill counts	1.9 (3)
Blood assays/lab values	51.3 (79)
Electronic monitoring (eg, electronic pill bottle, electronic pill box)	0.6 (1)
Response to treatment/medication	49.4 (76)
Disease severity	24.7 (38)
Other (eg, home videos)	1.3 (2)
None	5.8 (9)
Rating of adherence monitoring in clinic/practice (mean ± SD)	2.96±1.29
Poor	9.1 (14)
Fair	32.5 (50)
Good	28.6 (44)
Very good	20.8 (32)
Excellent	1.3 (2)
N/A: we do not monitor adherence	7.8 (12)

Abbreviations: IBD, inflammatory bowel disease; MMAS, morisky medication adherence scale; MAM, medical adherence measure; BMQ, brief medication questionnaire; MARS, medication adherence rating scale; AMBS/PMBS, adolescent/parent medication barriers scale, TRAQ, transition readiness assessment questionnaire; N/A, not applicable.

participants (24.7%) endorsed using a validated (ie, psychometrically tested for reliability and validity) screener to assess patient adherence, which is typically reviewed with the patient and family (18.8%), reviewed by the medical team (17.5%), and/or used to make changes to patients' treatment regimen (13.0%) or develop action plans (12.3%). Most frequently used methods for monitoring adherence included patient self-report (87.7%), parent/caregiver report (78.6%), blood assays/lab values (51.3%), and patient response to treatment/medication (ie, changes in a patient's symptoms while on a medication) (49.4%).

Adherence intervention practices

Table 3 shows that 70.1% of participants reported providing adherence-focused intervention to patients with poor/low adherence. Half of respondents defined poor/low adherence as missing at least 25% of medication doses, and another 37% defined poor/low adherence as missing at least 50% of medication doses. The most frequently endorsed types of adherence intervention included education on consequences of poor adherence (64.3%), education on strategies for improving adherence (61.7%), identifying adherence barriers (52.6%), and simplifying the treatment regimen (48.7%). Such intervention is provided largely by nursing

Table 3 Adherence intervention practices (n=154)

Practice characteristic	% (n)
Provision of adherence intervention for poor adherence (% yes)	70.1 (108)
Adherence intervention type	
Education on consequences of poor adherence	64.3 (99)
Education on strategies for improving adherence	61.7 (95)
Modeling appropriate way to carry out treatment plan	20.1 (31)
Pill swallowing training	26.0 (40)
Increased provider supervision/monitoring	20.8 (32)
Increased parental supervision/monitoring	35.1 (54)
Written treatment plans	32.5 (50)
Simplifying treatment regimen	48.7 (75)
Changing treatment regimen	33.1 (51)
Identifying adherence barriers	52.6 (81)
Problem solving to target adherence barriers	45.5 (70)
Use of electronic reminders (eg, alarm, texting)	27.9 (43)
Electronic monitoring (eg, MemsCap, Maya pillbox, MedSignals)	3.2 (5)
Other (eg, referral to Behavioral Medicine)	0.6 (1)
Intervention provider	
Physician	31.2 (48)
Nursing staff	51.9 (80)
Nurse practitioner	37.7 (58)
Psychologist	26.6 (41)
Social worker	14.9 (23)
Other (eg, child life specialist, pharmacist, OT)	4.5 (7)
Intervention modality	
Face-to-face during clinic visit	70.1 (108)
Over the phone	34.4 (53)
Via educational handouts	22.1 (34)
Via web-based education	3.9 (6)
Other	0.0 (0)
Rating of adherence intervention in clinic/practice (mean \pm SD)	
Poor	14.3 (22)
Fair	27.9 (43)
Good	32.5 (50)
Very good	16.9 (26)
Excellent	1.9 (3)
N/A: we do not provide adherence intervention	6.5 (10)

Abbreviations: OT, occupational therapist; N/A, not applicable.

staff (51.9%), nurse practitioners (37.7%) or physicians (31.2%), and usually conducted face-to-face during clinic visits (70.1%).

Overall, participants were asked to rate the level of adherence monitoring in their clinic/practice, from “poor” to “excellent”. On average, ratings were fair (32.5%) or good (28.6%; Table 2). Participants were also asked to rate the level of adherence intervention in their clinic/practice, on the same scale. On average, ratings were fair (27.9%) or good (32.5%; Table 3). Finally, participants were asked what might facilitate greater adherence monitoring and intervention in their clinic/practice. The most frequently endorsed responses were more staff/manpower (63%), education on

evidence-based screening measures (55.2%), and education on evidence-based interventions (56.5%).

General attitudes toward adherence practices

Overall, most participants felt that adherence intervention should be the responsibility of the physician (91.6%), nursing staff (73.4%), or nurse practitioner (70.1%). Approximately half of the participants perceived that psychologists and social workers should be responsible for providing adherence-focused intervention. In terms of nonadherence prevalence, most participants (90.3%) rated that no more than half of the children aged 0–12 take <80% of their prescribed medication, and 66.2% rated that no more than half of the adolescents take <80% of their prescribed medication. A larger proportion of participants endorsed greater rates of nonadherence in adolescents compared with children. Forgetfulness, being asymptomatic, and poor organization were identified as perceived primary adherence barriers for patients and families by survey participants.

Participants were asked to rate how important they perceive routine adherence monitoring to be in clinical practice, from “not important at all” to “very important”. Responses were as follows: neutral (3.9%), important (35.1%), and very important (61%). No participants rated adherence monitoring as “not important at all” or “not important at all”. Participants were also asked to rate the level of impact they perceive medication adherence to have on patients’ clinical outcomes, from “none” to “a lot”. The majority of respondents endorsed perceived impact as “a lot” (82.5%). Additionally, participants were asked to rate the level of change they feel they can elicit in patients’ adherence barriers, on a scale ranging from “none” to “a lot.” Approximately 20% endorsed feeling that they can elicit “a lot” of change and 72.1% endorsed “some.” Finally, participants were asked to identify primary barriers to doing routine adherence monitoring and intervention as part of standard clinical care (Table 4). The most frequently endorsed responses included lack of clinic time (73.4%), lack of manpower and resources (64.3%), and lack of staff with skills/expertise to target adherence and provide intervention (63.6%).

Discussion

To our knowledge, this is the first study to summarize current adherence monitoring and intervention practices in pediatric GI and hepatologic care across the USA. Our survey identified current practices across adherence monitoring and intervention, examined the most common barriers to

Table 4 General practice perspectives (n=154)

Practice characteristic	% (n)
Poor/low adherence defined	
Patient misses at least 25% of medication doses	49.4 (76)
Patient misses at least 50% of medication doses	37.0 (57)
Patient misses at least 75% of medication doses	2.6 (4)
Patient misses at least 100% of medication doses	0.6 (1)
Other (eg, combination of factors, missed appointments, missed labs, poor follow-through with behavior plan)	10.4 (16)
Perceived importance of routine adherence monitoring in clinical practice	4.57±0.57
Not important at all	0.0 (0)
Not important	0.0 (0)
Neutral	3.9 (6)
Important	35.1 (54)
Very important	61.0 (61)
Perceived impact of medication adherence on patients' clinical outcomes	4.79±0.54
None	0.6 (1)
Very little	0.0 (0)
Neutral	1.9 (3)
Some	14.9 (23)
A lot	82.5 (127)
Perceived ability to elicit change in patients' adherence behaviors	4.11±0.58
None	0.6 (1)
Very little	0.6 (1)
Neutral	5.8 (9)
Some	72.1 (111)
A lot	20.8 (32)
Perceived barriers to routine adherence monitoring in clinical care	64.3 (99)
Lack of manpower and resources	63.6 (98)
Lack of staff with skills/expertise to target adherence and provide intervention	73.4 (113)
Lack of clinic time	18.8 (29)
Lack of clinic space	8.4 (13)
Adherence is not a priority of our clinical care	3.9 (6)
Other (eg, insurance reimbursement)	
Perceived individual responsible to provide adherence intervention	
Nursing staff	73.4 (113)
Physician	91.6 (141)
Nurse practitioner	70.1 (108)
Psychologist	54.5 (84)
Social worker	46.1 (71)
Other (eg, parents, pharmacist)	6.5 (10)
Primary adherence barriers for children and adolescents	
Forgetfulness	61.7 (95)
Poor organization	46.8 (72)
Interference with extracurricular activities	27.3 (42)
Difficulty swallowing pills	10.4 (16)
Side effects	19.5 (30)
Being away from home	11.0 (17)
Changes in daily schedule/routine	25.3 (39)
Not wanting to feel different from other youth	40.9 (63)
Belief that medication is not working	21.4 (33)
Complexity of medication regimen	22.7 (35)

(Continued)

Table 4 (Continued)

Practice characteristic	% (n)
Misunderstanding directions for taking medications	11.7 (18)
Feeling fine, being asymptomatic	54.5 (84)
Cost	7.8 (12)
Other (eg, taste/texture of medication, parent attitudes)	5.2 (8)
Proportion of children (ages 0–12) taking <80% of prescribed medication	
<25%	47.4 (73)
26%–50%	42.9 (66)
51%–75%	7.1 (11)
>75%	2.6 (4)
Proportion of adolescents (ages 13+) taking <80% of prescribed medication	
<25%	14.9 (23)
26%–50%	51.3 (79)
51%–75%	29.9 (46)
>75%	3.9 (6)

implementing this in practice, and evaluated general attitudes toward adherence monitoring. Overall, data suggest significant variability in practices.

There are several notable strengths to current adherence practices, starting first with the high proportion of participants who endorsed doing adherence monitoring as part of standard clinical care. It does seem that for many participants, adherence monitoring occurs only for a subset of patients, typically based on diagnosis or treatment regimen. Most pediatric GI/hepatologic providers rely on patient and caregiver self-report of adherence, which have not shown great accuracy and usually result in overestimates of medication adherence.^{6,15} However, approximately half of pediatric GI/hepatologic providers are using objective measures as markers of adherence, including blood assays, lab values, and patient response to treatment/medication. It remains unclear whether these objective measures are being sought specifically for purposes of adherence monitoring. Providers are encouraged to exercise caution when using patient/parent-report of adherence, as it is not uncommon for patients/parents to experience difficulty remembering missed doses, or to inflate adherence estimates in order to be viewed favorably by their medical providers. A multi-method approach to adherence assessment which combines subjective and objective measures, for example, self-report and pharmacy records, is likely to provide the most valid estimates of patient adherence.

Another strength of current adherence practice is the high prevalence of providers who deliver targeted intervention to patients with poor adherence. This is done either by identifying and targeting adherence barriers and/or providing

education to families about the importance of adherence, or about strategies to improve medication-taking. This is notable given that greater adherence barriers are associated with greater difficulty in following prescribed medical regimens.^{16,17} Relatedly, adherence promoting interventions, which specifically identify adherence barriers and utilize problem-solving skills training to address these barriers, have shown great promise in pediatric IBD^{18–20} and other pediatric populations.^{21,22} Identifying and targeting adherence barriers is thus an essential first step toward improving patient adherence. Also, the goal of education is to increase patient's/family's knowledge of the disease, treatment, and the importance of adherence. There is evidence that educational approaches are effective when combined with behavioral strategies, but they appear to produce insignificant change in adherence when used in isolation.²³

Shared responsibility across disciplines for monitoring patient adherence and providing intervention is yet another strength of current adherence practices, as each member of the medical team can address different areas of need. Physicians and nurse practitioners might target education about the disease and treatment, education regarding the importance of adherence, and guided problem-solving concerning adherence barriers, while behavioral health providers (eg, psychologist, social worker) might address psychosocial factors impeding adherence. In fact, adherence promotion intervention that is delivered by medical providers among youth with chronic medical conditions has been evaluated and shown to be effective at improving patient adherence.²⁴ One study, which evaluated the effectiveness of a nurse-administered adherence intervention among youth with HIV, revealed significant improvements in patient knowledge of their disease and treatment, medical refill history, and self-reported adherence.²⁵ Shared responsibility for patient adherence is likely to be most effective when roles and responsibilities are clearly defined and communicated among team members. Without clear communication, team members might pass on the responsibility for adherence monitoring/intervention or incorrectly assume that someone else is targeting a patient's adherence.

Survey participants endorsed a number of barriers to conducting routine adherence monitoring in clinical care, which might partly explain participants' low ratings of the quality of both adherence monitoring and intervention in their practice. Such barriers might also explain why over 70% of respondents perceived having only "some" impact on patient adherence behaviors, despite perceiving adherence monitoring to be very important and as having significant

impact on clinical outcomes. Primary barriers included lack of manpower and resources, lack of staff with skills/expertise to target adherence and provide intervention, and lack of clinic time. While some of these barriers can be difficult and time consuming to remedy, clinical recommendations for providers looking to implement adherence monitoring and intervention are available.²⁶ These might include asking patients about difficulty in sticking to a medication regimen at every clinic visit, providing patients with pill boxes and/or a list of smartphone apps designed to provide medication-taking reminders, or collaboration with social work and psychology to address psychosocial adherence barriers. In addition, self-report questionnaires that assess adherence and adherence barriers are available, many of which are validated, quick to administer and score, require little to no training, and are clinically useful to guide appropriate and timely intervention.²⁷ It is also noteworthy that most participants underestimated the proportion of children and adolescents experiencing poor adherence. Research has actually shown that across pediatric conditions at least 50% are not taking medication as prescribed.² This discrepancy between provider estimates and published adherence rates might deter providers from prioritizing medication adherence as a pertinent clinical target during patient visits.

Overall, our study sample consisted of providers with diverse practices and clinical experiences across the USA, thereby enhancing the generalizability of study findings. Generalizability to private practices or other settings, however, may be low given that most participants practiced within children's hospital settings, either free-standing or housed within a larger hospital. In addition, participants largely comprised physicians, nurse practitioners, and psychologists, all provider types who were identified by participants as being primarily tasked with adherence monitoring and/or intervention. This suggests that study findings are likely an accurate representation of current clinical practices surrounding adherence in pediatric GI and hepatologic care. Despite high nonadherence rates in pediatric gastroenterology and hepatology, little is known about clinical practices around adherence to prescribed treatment regimens in this field. Improved understanding about current adherence monitoring and intervention practices is therefore an important step toward developing a more comprehensive, evidence-based, and systematic approach to promoting adherence in pediatrics. This might ultimately promote better adherence behaviors across the pediatric to adult care continuum. Since the current study relied on subjective reports of clinical practices by providers, findings may be an overestimate of adherence

monitoring and intervention practices. Future studies that employ objective (eg, observational) methods to evaluate adherence practices might provide more valid estimates. By evaluating the extent to which pediatric GI programs are incorporating objective outcomes assessment and utilizing evidence-based adherence interventions, we will be able to identify gaps and future directions in program development to improve adherence and, ultimately, health outcomes in youth with GI and hepatologic disorders.

Disclosure

The authors report no conflicts of interest in this work.

References

- Sabate E, Organization WH. *Adherence to Long-Term Therapies: Evidence for Action*. Geneva: World Health Organization; 2003.
- Rapoff M. *Adherence to Pediatric Medical Regimens*. New York, NY, USA: Kluwer Academic; 2010.
- McGrady ME, Hommel KA. Medication adherence and health care utilization in pediatric chronic illness: a systematic review. *Pediatrics*. 2013;132(4):730–740.
- Osterberg L, Blaschke T. Adherence to medication. *N Engl J Med*. 2005;353(5):487–497.
- Logan D, Zelikovsky N, Labay L, Spergel J. The illness management survey: identifying adolescents' perceptions of barriers to adherence. *J Pediatr Psychol*. 2003;28(6):383–392.
- Hommel KA, Davis CM, Baldassano RN. Objective versus subjective assessment of oral medication adherence in pediatric inflammatory bowel disease. *Inflam Bowel Dis*. 2009;15(4):589–593.
- Ingerski LM, Baldassano RN, Denson LA, Hommel KA. Barriers to oral medication adherence for adolescents with inflammatory bowel disease. *J Pediatr Psychol*. 2010;35(6):683–691.
- Schurman JV, Cushing CC, Carpenter E, Christenson K. Volitional and accidental nonadherence to pediatric inflammatory bowel disease treatment plans: initial investigation of associations with quality of life and disease activity. *J Pediatr Psychol*. 2011;36(1):116–125.
- Kane S, Huo D, Aikens J, Hanauer S. Medication nonadherence and the outcomes of patients with quiescent ulcerative colitis. *Amer J Med*. 2003;114(1):39–43.
- Higgins PD, Rubin DT, Kaulback K, Schoenfield PS, Kane SV. Systematic review: impact of non-adherence to 5-aminosalicylic acid products on the frequency and cost of ulcerative colitis flares. *Aliment Pharmacol Ther*. 2009;29(3):247–257.
- Fredericks EM, Lopez MJ, Magee JC, Shieck V, Opiari-Arrigan L. Psychological functioning, nonadherence and health outcomes after pediatric liver transplantation. *Am J Transplant*. 2007;7(8):1974–1983.
- Dobbels F, Van Damme-Lombaert R, Vanhaecke J, De Geest S. Growing pains: non-adherence with the immunosuppressive regimen in adolescent transplant recipients. *Pediatr Transplant*. 2005;9(3):381–390.
- Aitken M, Valkova S. *Avoidable Costs in US. Healthcare: The \$200 Billion Opportunity from Using Medicines More Responsibly*. Parsippany, NJ, USA: IMS Institute for Healthcare Informatics; 2013.
- Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap) – a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;42(2):377–381.
- Modi AC, Lim CS, Yu N, Geller D, Wagner MH, Quittner AL. A multi-method assessment of treatment adherence for children with cystic fibrosis. *J Cyst Fibros*. 2006;5(3):177–185.
- Simons LE, McCormick ML, Devine K, Blount RL. Medication barriers predict adolescent transplant recipients' adherence and clinical outcomes at 18-month follow-up. *J Pediatr Psychol*. 2010;35(9):1038–1048.
- McCormick King ML, Mee LL, Gutierrez-Colina AM, Eaton CK, Lee JL, Blount RL. Emotional functioning, barriers, and medication adherence in pediatric transplant recipients. *J Pediatr Psychol*. 2014;39(3):283–293.
- Hommel KA, Hente E, Herzer M, Ingerski LM, Denson LA. Telehealth behavioral treatment for medication nonadherence: a pilot and feasibility study. *Eur J Gastroenterol Hepatol*. 2013;25(4):469–473.
- Hommel KA, Hente EA, Odell S, et al. Evaluation of a group-based behavioral intervention to promote adherence in adolescents with inflammatory bowel disease. *Eur J Gastroenterol Hepatol*. 2012;24(1):64–69.
- Hommel KA, Herzer M, Ingerski LM, Hente E, Denson LA. Individually-tailored treatment of medication nonadherence: a Pilot Study. *J Pediatr Gastroenterol Nutr*. 2012;53(4):435–439.
- Wysocki T, Harris MA, Buckloh LM, et al. Effects of behavioral family systems therapy for diabetes on adolescents' family relationships, treatment adherence, and metabolic control. *J Pediatr Psychol*. 2006;31(9):928–938.
- Modi AC, Guilfoyle SM, Mann KA, Rausch JR. A pilot randomized controlled clinical trial to improve antiepileptic drug adherence in young children with epilepsy. *Epilepsia*. 2016;57(3):e69–e75.
- Kahana S, Drotar D, Frazier T. Meta-analysis of psychological interventions to promote adherence to treatment in pediatric chronic health conditions. *J Pediatr Psychol*. 2008;33(6):590–611.
- Rohan JM, Drotar D, Perry AR, McDowell K, Malkin J, Kerckmar C. Training health care providers to conduct adherence promotion in pediatric settings: an example with pediatric asthma. *Clin Pract Pediatr Psychol*. 2013;1(4):314–325.
- Berrien VM, Salazar JC, Reynolds E, McKay K; HIV Medication Adherence Intervention Group. Adherence to antiretroviral therapy in HIV-infected pediatric patients improves with home-based intensive nursing intervention. *AIDS Patient Care STDs*. 2004;18(6):355–363.
- Hommel KA, Greenley RN, Maddux MH, Gray WN, Mackner LM. Self-management in pediatric inflammatory bowel disease: a clinical report of the North American Society for pediatric gastroenterology, hepatology, and nutrition. *J Pediatr Gastroenterol Nutr*. 2013;57(2):250–257.
- Nguyen TM, La Caze A, Cottrell N. What are validated self-report adherence scales really measuring?: a systematic review. *Br J Clin Pharmacol*. 2014;77(3):427–445.

Therapeutics and Clinical Risk Management

Publish your work in this journal

Therapeutics and Clinical Risk Management is an international, peer-reviewed journal of clinical therapeutics and risk management, focusing on concise rapid reporting of clinical studies in all therapeutic areas, outcomes, safety, and programs for the effective, safe, and sustained use of medicines. This journal is indexed on PubMed Central, CAS,

Submit your manuscript here: <http://www.dovepress.com/therapeutics-and-clinical-risk-management-journal>

Dovepress

EMBASE, Scopus and the Elsevier Bibliographic databases. The manuscript management system is completely online and includes a very quick and fair peer-review system, which is all easy to use. Visit <http://www.dovepress.com/testimonials.php> to read real quotes from published authors.