Original article

Psychological predictors of nutritional adherence in adolescents with cystic fibrosis

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S U M M A R Y

Background & aims: The CF medical regimen is notoriously burdensome, comprised of respiratory treatments, oral medications, and nutritional demands. Adequate caloric intake has been identified as a challenge over the lifespan; however, we lack detailed information about nutritional adherence in teens, and the contextual drivers of these behaviors. Adolescence is a time of increased responsibility, reduced parental monitoring, and growing peer connections. There is no literature examining the impact of familial attitudes (e.g., privacy, disease disclosure) and the social milieu (e.g., friendships) on teen nutritional adherence behavior. We hypothesized that better teen nutritional adherence behaviors would be predicted by more favorable familial privacy attitudes, better relationship quality, and greater comfort in disease disclosure.
Methods: Assessment included questionnaires of caregiver privacy attitudes, relationship quality, and disease disclosure. Teens tracked PERT adherence for 1 month and logged daily caloric intake for 2 weeks. This produced detailed information on daily enzyme adherence, caloric intake, and eating frequency.
Results: Average PERT adherence, caloric intake, and eating frequency were suboptimal in this sample. More comfort in disease disclosure and less teen/mother discord predicted better PERT adherence. Higher caregiver privacy and lower teen closeness with friends predicted greater caloric intake and eating frequency.
Conclusions: Results suggest that comfort in disease disclosure supports consistent PERT adherence across environments. Adolescents with close friendships may have less time for self-management (e.g., eating). Future research should collect more detailed information about friendships of teens with CF. Results suggest that daily structure and positive, appropriately supportive relationships should be encouraged by care teams.

1. Introduction

Cystic fibrosis (CF) is an inherited genetic disorder which causes recurrent lung infections and progressive failure of multiple organ systems [1], necessitating a burdensome medical regimen that increases in complexity as the disease progresses. The nutritional demands of children with CF are complex due to their difficulty absorbing nutrients and gaining weight [2]. Body mass index (BMI) percentile is a critical factor in CF health outcomes, serving as a predictor of lung function and mortality across the lifespan [3–5]. Guidelines put forth by the Cystic Fibrosis Foundation (CFF)

recommend calorie intake between 110 and 200% of the daily energy needs for youth without CF, maintenance of BMI at the 50th percentile or higher, 40% of calories from fat, three meals and two to three snacks per day, and use of pancreatic enzyme replacement therapy (PERT) for pancreatic insufficient patients [6]. In 2016, the median BMI percentile of children and adolescents (age 2–19) with CF was the 55th percentile [7]. While this is a marked improvement from previous years, almost half of youth with CF continue to fall short of nutritional health goals.

One factor contributing to sub-optimal nutritional intake is non-adherence to energy intake and enzyme recommendations. Previous research using objective measures (e.g., Medication Event Monitoring System [MEMSCaps]) showed daily PERT adherence among adolescents ranged from 42.5% to 77.1% [8,9]. Adolescents' self-reported adherence to the high-calorie, high-fat diet is also

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low. Although adolescents with CF consume more overall calories and calories from fat than their peers without CF, they are not achieving the CF dietary recommendations [10—12]. Little is known about other nutritional adherence behaviors among adolescents with CF, as no research has collected comprehensive data that includes all components of nutritional recommendations including caloric intake, eating frequency (i.e., number of daily meals and snacks), and enzyme adherence. A critical gap in the literature is a comprehensive understanding of enzyme use and nutrition patterns (e.g., skipping meals, skipping enzymes, or skipping both meals and enzymes).

Complete nutritional adherence is particularly relevant information for adolescents, who are growing in independence and spending more time outside of the home and with peers. As autonomy increases and peer relationships become more dominant, children and adolescents with CF may attempt to conceal their CF symptoms and diagnosis in order to appear "normal" to their friends [13]. If an adolescent is attempting to conceal a CF diagnosis from friends, he or she may be less adherent to the medical regimen, and nutrition recommendations specifically. While research has examined the impact of friendship quality on adherence in children and adolescents [14,15], this research focused on respiratory adherence behaviors. Given that attitudes towards disclosure of personal information often begin within the family system, examining adolescent-parent relationships and family beliefs about privacy and information sharing may also shed light on understanding the interplay among these factors. Currently, little is known about disease disclosure behaviors in adolescents, and no work has examined associations between nutritional adherence, disclosure, caregiver attitudes toward privacy, and relationship quality in this age group.

The objectives of the current study were to 1) describe nutritional adherence behaviors (operationalized as caloric intake, percent fat in diet, eating frequency, and PERT adherence) in a sample of adolescents with CF and 2) examine associations between nutritional adherence behaviors and disclosure, caregiver privacy attitudes, and caregiver and friend relationship quality. We hypothesized that better PERT adherence, high caloric intake, and greater eating frequency would be predicted by more comfort in disease disclosure, families with more favorable attitudes towards sharing private information, and better relationship quality with caregivers and friends.

2. Materials and methods

2.1. Sample recruitment

The present study used a longitudinal design to assess nutritional adherence behaviors in adolescents with CF ages 12—17 years. Inclusion criteria were a confirmed diagnosis of CF with pancreatic insufficiency, current prescription for enzymes, access to the internet, and proficiency in reading English. Exclusion criteria were a diagnosis of developmental delay or intellectual disability, history of a lung transplant, or a diagnosis of CF-related diabetes. All eligible adolescents who met inclusion and exclusion criteria and their caregiver were sent a study letter, flyer, and do not contact postcard from the CF Center director inviting the family to participate in the study. If a postcard was not returned within 10 days of mailing, families were contacted by phone or approached at their next clinic visit by study personnel to explain more about the study, assess the family's interest in participation, and schedule a study visit. Thirty-one adolescent/caregiver dyads were approached; 9 declined to participate, resulting in a final sample size of 21 adolescents and their caregiver. Sample demographic characteristics

are detailed in Table 1, and psychosocial sample characteristics are detailed in Table 2.

2.2. Study procedure

If the caregiver and adolescent agreed to participate, they completed informed consent and assent with study staff. Adolescents could also agree to share their dietary data with their clinic dietitian to inform clinical care. If they declined, they remained eligible to participate in the study. Study data were collected and managed using REDCap electronic data capture tools hosted at a large Midwestern children's hospital [16]. This study was conducted in accordance with the amended Declaration of Helsinki. Local institutional review boards approved the protocol, and written informed consent was obtained from all patients (Cincinnati Children's Hospital Medical Center, Institutional Review Board - Federalwide Assurance #00002988; Study ID Number: 2016—7955).

During the initial study visit, study staff met with the family and assisted them in completing questionnaires. Families received up to five MEMSCaps (for use at home and school) and adolescents downloaded Myfitnesspal™ and logged into a unique study account provided to them. Adolescents borrowed iPads to use Myfitnesspal™ if their mobile device was incompatible. Study staff explained guidelines for use of Myfitnesspal™, including practical use of the app and the importance of precision and consistency in

Table 1
Sample characteristics.

	% (n)
Female	52.4% (11)
Caucasian	100.0% (21)
Annual household income	
<$20,000	4.8% (1)
$20,000—$39,999	19.0% (4)
$40,000—$59,999	9.5% (2)
$60,000—$99,999	38.0% (8)
>$100,000	28.5% (6)
Insurance status	
Private	76.2% (16)
Public	23.8% (5)

	M, range
Age	15.21 (12.23—17.83)
FEV1%	91.09 (40—111)
BMI percentile	59.61 (0.52—94.05)

Table 2
Psychosocial measures.

	M, SD
CF Disclosure Scale[a]	
CFDS Total	8.04 (1.54)
Comfort in Disclosure Activities	7.73 (2.39)
Comfort in Discussion	8.36 (1.81)
Family Privacy Orientation[b]	
Caregiver External	3.71 (1.21)
Network of Relationships Inventory	
Discord Mother[c]	2.21 (0.75)
Closeness Friends[d]	3.75 (0.86)

[a] Higher scores indicate greater adolescent-reported comfort in disclosure behaviors.
[b] Higher scores indicate higher levels of caregiver-reported openness with private information outside of the family.
[c] Higher scores indicate higher levels of adolescent-reported conflict with their mother.
[d] Higher scores indicate higher levels of adolescent-reported closeness with friends.

dietary logs. Adolescent participants were compensated $3 for each day of diet tracking completed.

2.3. Measures

2.3.1. Medical Information

Health information, including BMI, FEV$_1$, and prescribed treatment regimen, was abstracted from the adolescent's medical record. Participants used MEMSCaps for one month to track adherence to PERT and tracked their dietary intake including eating frequency for two weeks during this same period using Myfitnesspal™. MEMSCaps are a pill bottle which tracks adherence behavior digitally in real-time. There is an embedded computer chip in the bottle cap which records when the bottle is opened to dispense medication. The use of multiple MEMSCaps allowed this study to minimize error when measuring PERT usage.

2.3.2. Disclosure

A modified version of the Cystic Fibrosis Disclosure Scale (CFDS) [17] was used to assess disclosure behaviors in adolescents. The CFDS is a 20-item scale that asks participants to report whether they have disclosed their CF diagnosis to all, some, or no people in a relationship category (i.e., Close Friends, Casual Friends, Significant Other, Teachers, and Classmates). If they have disclosed, they then rate their comfort in performing disclosure tasks in front of those individuals (i.e., talking about their CF, taking enzymes, and doing lung treatments). A question regarding comfort taking enzymes was added given the focus of this study and included in scoring. Scores range from 1.0 to 10.0 and higher scores indicate greater comfort in disclosure. The CFDS demonstrates good internal consistency ($\alpha = .71$-.83).

2.3.3. Family Privacy Orientation

The adolescent and their caregiver each completed the Family Privacy Orientation measure (FPO) [18], a 12-item questionnaire that assesses caregiver and adolescent perception of their family's control and ownership of private information within and outside of the family. Scores range from 1.0 to 7.0 and higher scores indicate more openness in sharing private information. The FPO demonstrates good internal consistency ($\alpha = .78$-.83).

2.3.4. Family and Social Relationships

The Network of Relationships Inventory (NRI) was used to assess positive and negative qualities of the participants' social relationships [19]. Positive relationship qualities comprise the Closeness subscale (i.e., companionship, disclosure, support, approval, and satisfaction scales) and negative relationship qualities comprise the Discord subscale (i.e., conflict, criticism, pressure, exclusion, and dominance scales). Adolescents respond to each item on a Likert scale (1 = little or none to 5 = the most). Scores range from 1.00 to 5.00. Higher Closeness subscale scores indicate greater positive qualities, and higher Discord subscale scores indicate greater negative qualities. The NRI demonstrates good internal consistency ($\alpha = .80$).

2.4. Statistical analyses

MEMSCaps data were truncated at 100% each day to control for erroneous excess use on some days (e.g., miscalculation of enzymes needed, refilling bottle). A two-week "washout period" was built into this design to account for reactivity to MEMSCaps initiation [20]. The opening of the MEMSCaps bottle was cross-referenced with MyFitnessPal data to calculate PERT adherence. No washout period was built into diet data, since degradation of diet data is more common in the latter half of tracking due to the burden associated with self-monitoring [21]. Descriptive statistics are used to characterize the sample (see Tables 1—3). Relations among nutritional variables, psychosocial measures, and health outcomes were analyzed using longitudinal hierarchical linear modeling and t-tests (see Table 4). All analyses were conducted at a significance level of alpha <0.05. Corrections for multiple analyses were not implemented due to the small sample size and preliminary nature of this study and to avoid possible Type II errors. There were no missing data for the sample, as all participants logged complete dietary intake in MyFitnessPal for at least 4 days. Statistical analyses were completed using MPlus and performed by study staff with a doctoral-level statistician.

3. Results

3.1. PERT adherence

Participants in this sample demonstrated low PERT adherence rates, with a mean of 58.53%. Only one participant took enzymes with every meal and snack (see Table 3). PERT adherence was better in participants reporting greater comfort in disclosure activities ($R^2 = .170$, p < .01) and lower discord with their mother ($R^2 = .296$, p < .001). PERT adherence differed based on school day status (t (223) = -1.93, p = .05), with better adherence on school days (M = 65.61%, SD = .40) compared to non-school days (M = 54.70%, SD = .41). These associations are displayed in Table 4.

3.2. Dietary intake

The average number of days for which complete diet data were tracked in MyFitnessPal was 10.1 (Range = 4—14 days). On average, participants consumed close to 100% recommended daily intake (RDI) for energy; however, this falls below CFF recommendations and only five participants achieved an average RDI of at least 110%. Participants on average received 36% of their calories from fat, and five participants consumed at least 40% of calories from fat on average (see Table 3). Higher dietary intake was observed in participants whose caregivers reported more privacy with non-family members ($R^2 = .648$, p < .001), and participants reporting lower closeness with friends ($R^2 = .129$, p < .05). Specifically, lower levels of friendship approval ($R^2 = .241$, p < .001), friendship satisfaction ($R^2 = .199$, p < .01), and friendship support ($R^2 = .218$, p = .001) predicted higher dietary intake. See Table 4 for these longitudinal associations.

3.3. Eating frequency

Overall, participants in this sample ate slightly more than three times per day. Only one participant ate at least five times per day (see Table 3). Participants with higher FEV1 ($R^2 = .203$, p < .05) ate more frequently than participants with lower FEV1. Adolescents had increased frequency of eating when caregivers reported higher privacy with non-family members ($R^2 = .512$, p < .001) and lower closeness with friends ($R^2 = .140$, p < .001). Similar to dietary intake findings, lower levels of friendship approval ($R^2 = .284$, p < .001), friendship satisfaction ($R^2 = .136$, p < .05), friendship support ($R^2 = .147$, p < .05), and friendship companionship ($R^2 = .149$, p < .05) were identified as predicting higher eating frequency. These relationships are detailed in Table 4 at the end of this manuscript.

4. Discussion

This is the first study to use objective PERT adherence measures in conjunction with dietary self-monitoring to obtain a

Table 3
Sample nutritional adherence data.

	M (range)	CF Benchmarks	% of Sample Meeting Minimum Goal on Average
Percent RDI	96.71% (39.7—220.6%)	110—200%	23.8%
Percent Calories from Fat	36.61% (27.2—44.5%)	40%	23.8%
Daily Eating Frequency	3.35 (2.0—6.0)	5—6	4.7%
Daily Enzyme Adherence	58.53 (0.0—100.0)	100%	4.7%

Table 4
Results from longitudinal HLM examining the prediction of nutritional adherence behaviors by psychosocial and health variables.

	Standardized coefficients		95% CI		Effect size
	β	SE	Lower	Upper	R^2
PERT Adherence					
Psychosocial					
CFDS Overall	.412**	.156	.002	.013	.170
Caregiver external privacy	−.164	.236	−.146	.071	.027
Discord mother	−.544***	.138	−.303	−.096	.296
Closeness friends	.132	.235	−.106	.193	.018
Health					
FEV1	.188	.232	−.005	.012	.035
BMI %ile	.097	.229	−.004	.007	.009
Daily Caloric Intake					
Psychosocial					
CFDS Total	−.161	.215	−3.603	1.549	.026
Caregiver external privacy	−.803***	.067	−90.148	−42.360	.645
Discord mother	−.096	.247	−78.28	53.29	.009
Closeness friends	−.359*	.193	−80.757	−3.862	.129
Health					
FEV1	.113	.172	−1.387	2.874	.013
BMI %ile	−.203	.252	−3.196	1.432	.041
Eating Frequency					
Psychosocial					
CFDS Total	−.024	.175	−.015	.013	.001
Caregiver external privacy	−.716***	.104	−.573	−.207	.512
Discord mother	−.097	.180	−.398	.232	.009
Closeness friends	−.457***	.151	−.541	−.171	.209
Health					
FEV1	.451**	.148	.004	.036	.203
BMI %ile	.198	.217	−.007	.019	.039

*$p < .05$. **$p < .01$. ***$p < .001$.

comprehensive picture of adolescent nutritional adherence in CF. As has been found in other dietary studies, adherence to the energy recommendations is poor with only 24% of the sample achieving the minimum recommendations for percent calories from fat and RDI. Adherence to PERT was even lower with only 1 teenager taking PERT with every meal and snack. Given the aversive immediate digestive issues that often accompany not taking PERT with food, it was surprising, yet consistent with the literature, that on average teens only took PERT with 50% of their meals and snacks.

PERT was more consistently taken during the week than on weekends and by teens who reported greater disclosure comfort. The structure and routine of the school day may assist taking enzymes with meals and that teens who feel more comfortable in disclosure behaviors are more able to take enzymes at school meals [22]. Disclosure was not associated with nutritional intake or eating frequency. Taken together, these findings suggest that if an adolescent is uncomfortable with disclosure, PERT adherence outside of the home may be a challenge, and thus working to increase calories outside of the home may be a moot point.

Additionally, caregivers who reported less openness outside of the family had adolescents who consumed more calories and ate more meals and snacks. PERT adherence was not associated with family privacy. These results may indicate that more private families are spending more time together, which may include greater number of structured family meals. Of note, adolescent disease disclosure was not associated with the external privacy orientation of adolescents or caregivers, suggesting that disease disclosure is a separate construct from general privacy and openness. Thus, parents may not be setting the agenda, and adolescents instead develop CF-specific privacy behaviors outside of family modeling.

Teens who reported lower levels of discord with their mother demonstrated better PERT adherence, reflecting previous associations found between lower family conflict and better adherence to the CF nutrition regimen [23,24]. There were no associations between maternal relationship quality and nutritional intake or eating frequency. Associations between closer friendships and lower eating frequency and calorie intake are consistent with previous research on friendships in adolescents with CF [25]. Results may reflect that adolescents with closer friendships are spending more time with peers, leaving less time for daily care and reducing the amount of parental supervision.

4.1. Clinical implications

These results are targetable in a clinic setting. Care teams should first comprehensively assess adolescent nutritional adherence behaviors to identify areas for intervention. If the adolescent is struggling with PERT adherence, providers can further explore disease disclosure, daily structure, and family conflict. In teens who are less comfortable in disclosure activities, effective interventions may target increasing disclosure comfort through disclosure role plays or individual psychotherapy. Families can also problem-solve

with providers around implementing structure at home, particularly on days where the adolescent does not attend school. If family conflict is identified, the family may benefit from a family therapy referral to target discord and communication.

If an adolescent is struggling with caloric intake or eating frequency, providers may engage in problem solving around specific barriers during a clinic appointment, thoroughly assessing the family's daily structure and routines. Helpful strategies may include visual or shared calendars, automated reminders, or environmental changes to make snacks and food convenient and available for adolescents.

4.2. Limitations

Although appropriate statistical methods were used, the study included a small sample and conclusions drawn from results are therefore limited. Additionally, nutritional intake was based on self-report dietary tracking by adolescents, which likely contained some measure of error in recording. There is potential for error in recording with MEMSCaps, due to adolescents opening the bottle accidentally, for refills, etc.

5. Conclusions

Families and adolescents struggle to meet the CFF energy recommendations. PERT adherence and eating frequency were notably poor in this adolescent sample. Findings from this sample suggest that comfort in disclosure, caregiver privacy, daily structure, and positive family relationships are factors that can be addressed by clinicians and families. Future research is necessary to develop or identify interventions to target barriers to adolescent nutritional adherence.

Statement of authorship

All authors have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final approval of the version to be submitted.

Conflict of interest statement

No conflicts of interest exist for the authors of this manuscript.

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