CLINICAL INVESTIGATION

Evaluation of Medication-related Self-care Skills in Patients With Cystic Fibrosis

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BACKGROUND: As the life expectancy of patients with cystic fibrosis (CF) increases, the focus on ensuring success with medication therapies is increasingly important. The ability of patients to autonomously manage medications and related therapies is poorly described in the literature.

OBJECTIVE: The goal of this project was to assess the level of medication-related knowledge and self-care skills in patients with CF.

METHODS: This project took place in a Cystic Fibrosis Foundation accredited affiliate center. Eighty-nine patients between the ages of 6 and 60 were eligible to participate based on inclusion and exclusion criteria. Pharmacists administered a 16-item questionnaire and detailed medication history during clinic visits from January through May 2014.

RESULTS: Forty-five patients 6 to 41 years old participated in the study. The skills most often performed independently were preparing nebulizer treatments (85%) and telling someone if they feel their medicines are causing a problem (89%). Skills least often performed were carrying a medication list (82%) and bringing a medication list to appointments (76%). In respondents 21 years of age and older, less than 75% of respondents were involved with obtaining financial resources, maintaining equipment, carrying a medication list, or rinsing their mouth after using inhaled medicines. Participants were able to provide drug name, dose, and frequency of use for pancreatic enzymes and azithromycin 37% and 24% of the time, respectively.

CONCLUSIONS: In the population surveyed, many medication-related skills had not been acquired by early adulthood. Assessing and providing education for medication-related self-care skills at all ages are needed.

INDEX TERMS: cystic fibrosis, patient advocacy, quality improvement, self-care, self efficacy

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INTRODUCTION

Cystic fibrosis (CF) is a chronic, autosomal recessive disease affecting around 30,000 children and adults in the United States.¹ The life expectancy of patients with CF has increased to a median predicted survival age in 2014 reaching 39 years, with nearly half of the CF patient population being adults.¹ Medication management in the setting of CF can be daunting for patients and families, as time dedicated to completing treatment regimens may take up to 2 hours per day.² Because CF is demanding in terms of medication and treatment regimens, acquiring essential

skills are needed for successful transition from pediatric to adult care and to maintain health outcomes.³

The American College of Chest Physicians' (ACCP) Guidelines for Cystic Fibrosis Adult Care endorse ongoing evaluation for readiness to transition from pediatric to adult care, but do not give details regarding specific requirements of medication-related self-care skills.⁴ Along with the American Academy of Pediatrics (AAP), ACCP supports transition programs for adolescents with chronic diseases and CF, respectively.^{4,5} The AAP endorses the implementation of a step-by-step transition plan, which focuses on

acquisition and development of skills. The Cystic Fibrosis Foundation adult consensus guideline also recommends development of a plan for effective interventions to facilitate transition. A large factor in the assessment of transition readiness is a patient's ability to perform self-care skills, specifically related to medication management.⁵

In a recent study, qualitative research interviews were utilized to uncover themes of facilitation and barriers to adherence.⁶ One such facilitating theme was "recognizing the importance of therapies," which was identified as an area for intervention to improve skills.⁶ A survey of 76 parents of children with CF found a positive correlation between increases in treatment knowledge and a child's level of self-care independence.⁷ McLaughlin and colleagues⁸ concluded there is a need for greater emphasis on the importance of development of self-care skills, which included medication management. Current transition readiness assessments have a gap in evaluation of specific medication-related self-care skills.^{3,9-11}

Medication-related self-care skills identified in need of improvement both for the purpose of transition and overall independence of care will help establish plans for interventions, with the hope of improving outcomes related to transition readiness. The goal of this project was to assess the current level of medication-related knowledge and independence with self-care skills in patients with CF. Level of progression of knowledge and skills based on age was also important to assess in order to develop future intervention programs. Furthermore, this project may help in the development of a standard level of medication-related self-care skills and knowledge.

MATERIALS AND METHODS

Survey Tool

The previously validated Transition Readiness Assessment Questionnaire (TRAQ) was modified to assess medication-specific knowledge and skill.³ The TRAQ tool focused on overall general life skills, ranging from financial management to making physician appointments. This tool was chosen as a model because of its utilization in assessment of transition readiness for patients with a wide variety of chronic health conditions, including CF. In a recent systematic review of readiness assessments, the TRAQ tool was

identified as a tool with evidence of good validity and reliability for patient self-management skills.¹² Despite its use in this population, the most recent version of the TRAQ included only 5 questions assessing overall self-management of medications. Modifications were made to questions used in versions of the TRAQ to focus specifically on the assessment of medication skills and knowledge (Table 1). Approval by the University of Oklahoma Health Sciences Center Institutional Review Board was obtained prior to study initiation. Verbal consent or assent was required for participation and was obtained by the pharmacist investigators.

To assess appropriateness of the modified questionnaire, a pilot questionnaire was reviewed by clinic staff, which included nurses, pulmonologists, a dietitian, a social worker, and parents of children with CF. The pilot questionnaire with 18 questions was administered in the clinic between August and November 2013.

Modifications to the pilot were made based on feedback and included decreasing the questionnaire length by 2 questions. The revised questions were classified into 4 domains (Table 2). Changes were made to account for varying levels of health literacy and reading levels of younger participants. Ordinal patient responses were maintained to provide more information about patient skills and behaviors.

After the pilot period, a bank of cue questions was developed to be used during administration if a patient experienced difficulty answering a survey question, or required clarification to understand the question being asked. Use of cue questions was recorded during administration of revised questionnaires. Due to the varying age of study participants, summarizing the need for question cues would provide information on how well the questions were understood by participants of varying ages. Revised questionnaires were administered between January and May 2014.

Study Participants

Pharmacists determined eligibility and administered questionnaires during regularly scheduled office visits. Patients included in the study had to receive care at the CF Center and be at least 6 and no greater than 60 years of age. Patients were excluded if they primarily spoke a language other than English, had a history of

Table 1. Expansion of TRAQ Questions

TRAQ	Expanded (CF Specific)
Do you take medications correctly and on your own?	a) Can you tell me the order in which you take (or use) your inhaled medicines? b) Can you remember to take enzymes before eating without being reminded by someone else? c) Can you take other medicines without being reminded by someone else? d) Can you prepare nebulizer treatments?
Do you reorder medications before they run out?	a) Can you refill medicines before they run out? b) Do you know how to get refills if you run out of refills at the pharmacy?
Do you fill a prescription if you need to?	a) Can you fill your own prescriptions at your pharmacy?
Do you use and take care of medical equipment and supplies?	a) Do you sterilize your nebulizer and spacer daily? b) Do you replace filters in your breathing machine every 6 months? c) Do you replace nebulizer cups every 6 months?
Do you know what to do if you are having a bad reaction to your medications?	a) Do you tell someone if you think your medicines are causing a problem (i.e., parent or call the clinic)? b) Do you talk to someone at the CF clinic before starting a new medicine? c) Do you rinse your mouth out or brush your teeth after using nebulizer treatments and inhalers?
Do you pay or arrange payments for your medications?	a) (After age 16) Do you know how to obtain resources if you can't afford your medicines?
Do you fill out the medical history forms, including a list of your allergies?	a) Do you carry a complete list of your medicines with you? b) Do you bring a complete list of your medicines with you to all doctor's appointments?

CF, Cystic Fibrosis; TRAQ, Transition Readiness Assessment Questionnaire

lung transplantation, or had a diagnosis of CF-related metabolic syndrome. All investigators were trained to administer questionnaires in a manner designed to reduce subjectivity and improve consistency, thereby reducing interviewer bias. Parents or guardians were welcome to accompany the patient, but their participation during administration was discouraged.

Statistical Analysis

Patient responses were assessed using a Likert scale, where answers were assigned a point value ranging from 1 to 5; 1 point corresponding to the least knowledge or skill level and 5 points for the highest knowledge or skill level. Questionnaires also included a detailed assessment of medication histories, where patients were asked to provide names of medications, strengths of medications, doses, and frequency of dosing. Medication history scores were based on a point system corresponding to the degree of information about each medication the patient was able to provide and were scored independently from the question-

naire. Additional data collected included patient age in years, gender, and status of pancreatic function. Data from pilot questionnaires were analyzed separately from revised questionnaires, and patients were not permitted to participate in both pilot and revised questionnaires.

Univariate analyses were performed in order to explore central tendency and dispersion in the data, and produce descriptive summaries of the study group. Participants were categorized, for comparison purposes, into 8 age groups: 6 to 10 years, 11 to 15 years, 16 to 20 years, and greater than 21 years. Variables were compared, where appropriate, using t-tests for continuous data and chi-square tests for categorical data. Non-parametric equivalents were used as necessary. All analyses were completed using Statistical Analysis Software v9.3 (SAS Institute, Inc, Cary, NC) with an a priori alpha level of 0.05.

RESULTS

Eighty-two patients were eligible for inclu-

Table 2. Responses to Questionnaire

Question n (%) (total n = 45 unless otherwise noted)	Responses				
	No, and I Don't Want to Learn	No, but I Want to Learn	Yes, but I Never Do This	Yes, and I Sometimes Do This	Yes, and I Always Do This
Questions 1-6 Medications					
1. Can you tell me the order in which you take (or use) your inhaled medicines?	1 (2.2)	8 (17.8)	1 (2.2)	10 (22.2)	24 (53.3)
2. Can you remember to take enzymes before eating without being reminded by someone else? (N/A if pancreatic sufficient)	0 (0.0)	3 (6.7)	1 (2.2)	18 (40.0)	21 (46.7)
3. Can you take other medicines without being reminded by someone else?	0 (0.0)	9 (20.0)	1 (2.2)	17 (37.8)	18 (40.0)
4. Can you prepare nebulizer treatments?	3 (6.7)	4 (8.9)	0 (0.0)	4 (8.9)	34 (75.6)
5. Can you fill your own prescriptions at your pharmacy?	13 (28.9)	8 (17.8)	1 (2.2)	7 (15.6)	16 (35.6)
6. Can you refill medicines before they run out at home?	9 (20.0)	8 (17.8)	4 (8.9)	8 (7.8)	16 (35.6)
Questions 7-8 Access					
7. Do you know how to get refills if you run out of refills at the pharmacy?	10 (22.2)	15 (33.3)	1 (2.2)	6 (13.3)	13 (28.9)
8. (After age 16) Do you know how to obtain resources if you can't afford your medicines? (n = 24)	1 (4.2)	7 (29.2)	2 (8.3)	4 (16.7)	10 (41.7)
Questions 9-11 Equipment					
9. Do you sterilize your nebulizer and spacer daily?	2 (4.4)	5 (11.1)	12 (26.7)	12 (26.7)	14 (31.1)
10. Do you replace filters in your breathing machine every 6 months?	9 (20.0)	12 (26.7)	9 (20.0)	8 (17.8)	7 (15.6)
11. Do you replace nebulizer cups every 6 months?	6 (13.3)	5 (11.1)	5 (11.1)	7 (15.6)	22 (48.9)

CF, Cystic Fibrosis; N/A, not available.

Table 2. Responses to Questionnaire (cont.)

Question n (%) (total n = 45 unless otherwise noted)	Responses				
	Questions 12-16 Adverse Drug Reactions/Interactions	I Didn't Know That I Should Do That	I Didn't Know That I Should Do That, but Will in the Future	I Know That I Should Do That, but I Don't	I Know That I Should Do That, and Sometimes Do It
12. Do you tell someone if you think your medicines are causing problems (i.e., parent or call the clinic)?	3 (6.7)	1 (2.2)	1 (2.2)	1 (2.2)	5 (11.1)
13. Do you talk to someone at the CF clinic before starting a new medicine?	6 (13.3)	4 (8.9)	4 (8.9)	2 (4.4)	8 (17.8)
14. Do you carry a complete list of your medicines with you?	12 (26.7)	13 (28.9)	13 (28.9)	12 (26.7)	5 (11.1)
15. Do you bring a complete list of your medicines with you to all doctor's appointments?	9 (20.0)	12 (26.7)	12 (26.7)	13 (28.9)	7 (15.6)
16. Do you rinse your mouth out or brush your teeth after using nebulizer treatments and inhalers?	8 (17.8)	9 (20.0)	9 (20.0)	4 (8.9)	13 (28.9)
					11 (24.4)
					0 (0.0)
					0 (0.0)
					0 (0.0)
					0 (0.0)

CF, Cystic Fibrosis; N/A, not available.

sion. Of those eligible, 7 participated in the pilot questionnaire. Additionally, 7 eligible patients declined to participate during verbal consent. Forty-five patients were enrolled in the study and completed revised questionnaires (Figure 1). Twenty-three eligible patients were not enrolled due to absence of a clinic visit during the study period. Fifty-three percent of participating patients, ranging in age from 6 to 45, were greater than 16 years old ($n = 24$). Although not statistically significant, 62.2% of participants were male ($p = 0.1$). A majority of patients were pancreatic insufficient ($n = 43$, 95.6%).

In general, as participant age increased, the percent of patients responding that they have the knowledge to perform a skill and routinely perform that skill increased (Table 3). Based on the median number of "Yes" responses to the questions, all age groups generally were aware they should and were able to: state the order of use for their inhaled medicines (median = 5), take medicines without being reminded (median = 4), prepare their nebulizer treatments (median = 5), tell someone if their medicines are causing problems (median = 5), and rinse their mouth after inhaled medicines (median = 4). The items with the lowest overall percent of respondents in all age groups reporting "always": completing the task were: Filling their own prescriptions (median = 3.5), knowing how to get refills if none are left on the prescription (median = 2), replacing nebulizer cups as recommended (median = 4), carrying a medication list with them (median = 2), and bringing a medication list to medical appointments (median = 3). By age 21, less than half of the respondents reported carrying a medication list with them at any time or for medical appointments. Questionnaire responses with corresponding domains and results are illustrated in Table 2. Information regarding the proportion of participants who responded that they sometimes or always (Likert score of 4 or 5) are aware of and can perform the skill assessed by each individual question is illustrated in Table 4.

Figure 1. Patient participants

Questionnaire Medication Domain

Question 2 assessed a patient's knowledge of the necessity of taking enzymes before eating and their ability to remember without being reminded by someone else. On this question, the youngest and oldest age groups (6-10 years and those greater than 21 years) scored higher than both adolescent age groups. Question 4 demonstrated that as age increased, ability to prepare nebulizer treatments for administration also increased. Question 5 indicated that 13 patients (28.9%) did not have the skills to fill prescriptions nor the desire to learn how to do this, although the majority of patients with this response were in the age group 6 to 10 years. Two out of the 8 patients in the age group 16 to 20 years responded they did not have this skill, but wanted to learn how to fill prescriptions.

Questionnaire Access Domain

In regards to obtaining financial resources, it

was found that 29% of patients 16 years of age and older were unaware of how to obtain support for medication costs and wanted to learn how to do this.

Questionnaire Equipment Domain

Question 9 assessed patient skills regarding sterilization of their nebulizer and spacer. Sixty percent ($n = 6$) of participants in the age group 6 to 10 years and 36.4% ($n = 4$) in the age group 11 to 15 years responded that they were aware they should sterilize but do not. Sixty percent of patients ($n = 3$) in the greater than 21-year-old group responded that they sometimes sterilize equipment, demonstrating that self-care skills may decrease during early adulthood.

Questionnaire Adverse Drug Reaction/Interaction Domain

Thirteen patients (28.9%) knew they should bring a medication list to their doctors' appoint-

Table 3. Average Survey Percent Score by Age Group

Age Group (yr)	N	Average Survey Percent Score
6-10	10	46
11-15	11	61.7
16-20	8	71.7
21-45	16	87.2

ments but do not. Question 16 demonstrated that adolescents may not be aware of or adherent to recommendations to rinse out their mouth after using nebulizers or inhalers.

Medication Histories

Many of the core medications used by patients with CF were readily identified and many participants could provide additional information during medication histories. Thirty-one of 44 patients who use albuterol (70.5%) were able to identify the name (albuterol), dose, and frequency of use of the prescribed bronchodilator (Figure 2). Of the 43 patients with pancreatic insufficiency, 37.2% ($n = 16$) were able to identify all components of the associated medication history: enzyme name, dose (including strength and number of capsules), and frequency of use. An additional 48.8% ($n = 21$) were able to provide the enzyme name and frequency, but could not provide the complete dose (strength and number of capsules). Thirty-six out of 44 patients (81.8%) were able to identify the dose and frequency ($n = 10$) or the name, dose, and frequency of their multivitamin ($n = 26$). Sixty-five percent (17/26) of patients using inhaled tobramycin (either nebulization or inhalation powder) and 58% (25/43) of patients taking dornase alfa were able to provide all 3 components of the medication history, but only 50% (18/36) of patients on hypertonic saline were able to provide the same information. When evaluating several medications, a majority of patients were only able to identify the name and dosing frequency of their medication. As age increased, participants' overall scores were higher.

All patients in the youngest and oldest age groups required at least 1 cue; 10 out of 10 in the 6- to 10-year age group and the single participant in the 41 to 45 age group. On average, the 6- to 10-year-old participants required 1.7 cues per patient. Mean use of cues was 1.4 ($SD = 0.5$) and 2.3 ($SD = 0.6$) for the 6- to 7-year-old age group ($n = 7$) and the 9- to 10-year-old age group ($n =$

3), respectively ($p = 0.08$). The single 41 to 45 year age group participant required 2 cues during questionnaire administration. Use of cues was highest for questions 1 ($n = 15$) and 6 ($n = 7$).

DISCUSSION

This project demonstrates several points regarding medication self-care skills. Patients scored higher on questionnaires as age increased, which is to be expected. When assessing abilities to provide all 3 components of medication histories for medications commonly used in the treatment of CF, patients consistently were able to provide more information as age increased. Despite this observation, there were several adult patients who scored poorly on the questionnaire.

To our knowledge, this project is the first to assess and describe medication-related knowledge and skills in patients with CF. Based on these results, improvements in education could be made to emphasize important aspects of medication self-care management, such as always taking enzymes before eating, rinsing or brushing teeth after nebulizer or inhaler use, and equipment maintenance. One area of particular concern is that 29% of subjects 16 years and older were unaware of resources available to ensure access to medications, and other financial benefits. It also appeared that adolescents struggled with adherence to enzyme therapy and their ability to fill prescriptions when they are out. This highlights concerns as adolescents reach adulthood and are not equipped to independently provide their own care. These results reinforce that adolescent years can be a challenge for disease state management. Decrease in well-being has been noted during adolescent years in patients with chronic conditions resulting from a decrease in self-care.¹³

Although we did include patients starting at age 6, we did not expect this age group to be able to answer all of the questions. Aside from the younger age groups, very few participants chose "no and I don't want to learn" or "I don't know how and don't want to learn," demonstrating that a majority of patients are interested in educational opportunities regarding their healthcare. Future readiness assessments and educational programs will need to account for participant age and potentially adjust question selection in younger age groups. Future assessments may also take into consideration complex-

Table 4. Number of Always and Sometimes Responses to Each Question by Age Category

Question	6-10 yr (n = 10)	11-15 yr (n = 11)	16-20 yr (n = 8)	21 yr or Older (n = 16)
1	6 (60%)	8 (72.8%)	6 (75%)	14 (87.5%)
2	9 (90%)	9 (81.9%)	6 (75%)	15 (93.8%)
3	6 (60%)	8 (72.8%)	6 (75%)	13 (81.3%)
4	5 (50%)	10 (90.9%)	7 (87.5%)	16 (100%)
5	0 (—)	1 (9.1%)	6 (75%)	16 (100%)
6	0 (—)	4 (36.4%)	6 (75%)	14 (87.5%)
7	0 (—)	1 (9.1%)	5 (62.5%)	13 (81.3%)
8	0 (—)	0 (—)	5 (62.5%)	11 (68.8%)
9	1 (10%)	6 (54.6%)	7 (87.5%)	12 (75%)
10	0 (—)	2 (18.2%)	4 (50%)	9 (56.3%)
11	2 (20%)	8 (72.8%)	5 (62.5%)	14 (87.5%)
12	7 (70%)	9 (81.9%)	8 (100%)	16 (100%)
13	4 (40%)	7 (63.7%)	7 (87.5%)	15 (93.8%)
14	0 (—)	2 (18.2%)	0 (—)	6 (37.5%)
15	0 (—)	3 (27.3%)	1 (12.5%)	7 (43.8%)
16	6 (60%)	4 (36.4%)	3 (37.5%)	11 (68.8%)

ity of medication regimens as patients age and how knowledge and skills relate to number of prescribed medications.

The addition of the cue bank was made after the pilot period in order to provide some data to reflect on question wording and understanding. Cue use was highest for the initial question of the questionnaire. This may have been due to participants acclimating to questionnaire administration. It should also be noted that 10 out of the 15 cues used for question 10 regarding replacement of nebulizer filters were used in the 6- to 10-year-old age group. This may also support the use of a separate readiness tool for younger participants. Although all patients in the youngest age group (6-10 years) received cues, as a group, their responses and scores support they may be in early stages of skill development.

Patients were eligible to participate starting at 6 for several reasons. First, it has been recommended that children begin to develop skills, such as starting with the names and purposes of medications, with parental monitoring, throughout school-aged years and into adolescence.¹³ Secondly, Adult Care Consensus guidelines recommend initiating discussion about transitions of care early in a patient's life, and it is our belief that medication knowledge and skills

are an important part of transition readiness.⁴ Mastery of skills related to medication management may also decrease the chances of becoming overwhelmed as an adult. For example, Sawicki and colleagues³ identified financial issues as an area of improvement based on score results from the TRAQ. This supports acquiring basic skills needed for medication management earlier in life, so patients may focus on more complex goals during late adolescent years.

Level of medication knowledge was also an area of concern based on questionnaire results. Often patients were unable to provide specific details about their medications. Patients may be at risk for medication errors if they are seen by multiple providers or admitted to the hospital if they are unable to provide full details of their medications. It was noted that a majority of patients do not carry a medication list, which could help decrease errors.

Limitations

Although this takes place in specific patient population and a small, single CF center, participant demographics included a wide range of ages, and are potentially representative of other populations with CF. Sawicki and colleagues³ found significant gender differences in self-

Figure 2. Percent of total participants providing each level of medication detail by drug.

■ Name/Dose/Frequency; ■ Dose/Frequency; ■ Name/Frequency; ■ Name/Dose

advocacy scores when validating the TRAQ tool, a difference which was not seen in the current study. This difference could be due to a large variety of factors, including the small sample size.

Due to the specific nature of the project, modifications to the TRAQ tool were needed to meet the aims of the project. The small sample size impeded the ability to validate the current tool. Because patients were not allowed to participate in both pilot and revised questionnaires, this decreased the number of patients eligible to participate in the revised questionnaires. Piloting the questionnaire was an important step in the research project because the tool was not validated and provided vital information for tool development.

Although training occurred to improve internal validity of questionnaire administration, variations in the process of administration were unavoidable. Variations in interviewing methods or amount of prompting potentially could have affected scoring of the medication histories. Future studies should include a single interviewer as a variable in order to assess any potential systematic difference present in results. Medication history grading was kept consistent based on information provided, but generally, dosing information was graded more strictly if there were multiple strengths available (e.g., pancreatic enzymes) and less stringently if only a single strength was available (e.g., dornase alfa). Additionally, participants may have been hesitant to provide an answer that included an

unwillingness to learn a skill, leading to choosing a response with a more positive connotation.

CONCLUSION

Overall, this project describes the medication-related knowledge and skills of the patient population who participated in a modified version of a previously validated transition readiness assessment tool. Scores generally increased with increasing age, which is expected based on length of exposure to treatment. Despite this, many young adults were not able to complete many essential medication-related self-care skills. Periodically administering readiness assessments may improve patient knowledge and skills in preparation for transition to adult care.

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Abbreviations AAP, American Academy of Pediatrics; ACCP, American College of Chest Physicians; CF, cystic fibrosis; TRAQ, Transition Readiness Assessment Questionnaire

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