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Assessing psychosocial risk in pediatric cystic fibrosis

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Abstract

Background: Psychosocial risk factors are known to impact quality of life, treatment adherence, and health outcomes. No standardized comprehensive psychosocial risk screener is routinely utilized in cystic fibrosis (CF) care. The objectives of the study were to describe the range and severity of psychosocial risk within this CF population, investigate the reliability of a comprehensive psychosocial screener in pediatric CF clinical care, and explore relationships between psychosocial risk and key factors affecting health outcomes. It was hypothesized that the PAT-CF total and subscale α coefficients would be similar to those found in other pediatric medical populations.

Method: Parents of 154 children with CF completed a CF-specific version of the Psychosocial Assessment Tool_All-lit (PAT-CF), an empirically-based psychosocial risk assessment, during routine CF clinical care.

Results: The internal consistency of the PAT-CF Total score was 0.71. Total score and subscale reliabilities reflect findings in other pediatric populations. Total risk scores fell in the following categories: 7% (Clinical-highest risk), 41% (Targeted), and 52% (Universal-lowest risk), respectively. Increased psychosocial risk was associated with Medicaid status and lower parent education, whereas having private insurance was associated with decreased psychosocial risk.

Conclusions: The PAT-CF can feasibly be used as an empirically-based comprehensive psychosocial risk tool in routine CF care and is acceptable by parents. In addition to providing universal anticipatory guidance regarding child and family wellness, early identification of risk factors allows care teams to proactively provide targeted support and intervention for specific psychosocial risk factors to promote improved quality of life and ability to sustain daily care.

KEYWORDS
cystic fibrosis, psychosocial risk, screening, wellness

1 | INTRODUCTION

Cystic fibrosis (CF) is a chronic life-shortening disease associated with a complex, time-intensive daily treatment regimen that can feel burdensome for children and their caregivers. In addition, the unpredictability of symptoms and illness can have a significant

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impact on daily routines and quality of life. Given most children with CF are now identified through newborn screening, medical assessment and intervention can be initiated proactively. Similarly, we have the opportunity to attend to psychosocial factors proactively to promote positive outcomes early in life, foster family wellness,[1] and attend to conditions and situations that adversely impact the daily management of CF.[2] Suboptimal CF regimen adherence rates[3] highlight the need for identification of barriers to daily care to provide proactive targeted psychosocial intervention. Psychosocial interventions are designed to address the individual, family, social, and economic risk factors present in the environment in which children live. These risk factors are associated with health outcomes and mortality, including the cumulative stress from financial hardship, environmental risk factors, negative health behaviors, and barriers to accessing optimal health care.[3-5]

The impact of managing of a pediatric chronic illness, like CF, can have a variety of effects on the family system. First, caring for a child with CF may predispose parents to develop anxiety and depression[6] that impairs daily functioning. In addition to the stress of managing daily care, parents must navigate the complex health care landscape, including the medical environment, insurance companies, and pharmacies. Parents also work with complex school systems to ensure children are receiving the proper accommodations to promote optimal academic achievement[7] and health. Family relationships and the psychological functioning of the child with CF and family members can be impacted. Social relationships can also be difficult to maintain given the commitment to daily care and uncertainty of the illness. Problems with employment may contribute to financial hardship, which has wide-sweeping effects on the family system's ability to function. Indeed, socioeconomic status (SES) has been examined as one of the nongenetic factors that plays a role in lung function and growth, as well as the progression of CF disease. Examination of data from the CF Registry[8] found that Medicaid status was associated with a 3.65 times increased likelihood of mortality, after accounting for sex, race, pancreatic enzyme use, and age. O'Connor et al[9] supported these associations and found that patients were at decreased risk for death if they lived in zip codes with a higher median income.

A tool is needed in pediatric CF care to easily and comprehensively screen for psychosocial factors linked to health and well-being. The clinical screening process sets the stage for provider-patient conversations that, like medical assessment, allow for relationship building, reducing stigma, and provision of interventions targeted to the specific concern. Cystic Fibrosis Foundation (CFF)-accredited centers are recommended to have a minimum of one interaction between the individual with CF (and/or the caregiver) and with social work each year, as well as a mental health coordinator, and ideally this would include a comprehensive assessment of psychosocial risk. Use of a validated, standardized instrument that can efficiently and effectively assess psychosocial risk[10] is a vital step in delivering targeted care and interventions.

Until recently,[11] no guidelines existed regarding routine screening for psychosocial risk factors in CF. Annual screening for anxiety and depression in individuals with CF over the age of 12 and their caregivers is now being increasingly implemented in CF care in accordance with the 2016 CFF mental health guidelines. Another routinely used instrument is the Cystic Fibrosis Questionnaire-Revised (CFQ-R),[12] which is the gold standard assessment of global quality of life (QOL) in CF that includes QOL domains such as physical and emotional functioning and treatment burden. Although these validated measures provide key clinical information, their specificity does not allow for broader understanding of psychological functioning for the child and parents (ie, ADHD [attention deficit hyperactivity disorder] symptoms and substance use), assessment of the family environment and relationships, sibling functioning, social support, and financial functioning. Identification of a questionnaire that allowed for more extensive assessment of family system risk factors was needed for use in pediatric CF care.

The Psychosocial Assessment Tool (PAT)[13] is an empirically derived standardized, reliable, and valid comprehensive screening tool that can be used by medical and allied health providers to efficiently assess for psychosocial risk factors in need of attention within the family system. The PAT was initially developed and utilized with families of children newly diagnosed with cancer. The PAT is based on the Pediatric Preventative Psychosocial Health Model (PPPHM),[14] which consists of three risk stratification categories. Given the scoring structure of the PAT the majority of the families who complete the screener will fall, based on their total score, into the Universal risk category with fewer in the Targeted and Clinical categories. Families identified in the Universal risk category are generally capable of coping and adapting to their illness and its treatment demands due to having multiple social resources, and relatively few risk factors. They experience normal transient distress when faced with challenges and can adapt with education and support. Families in the Targeted risk category are at elevated risk due to acute distress and an increased number of psychosocial risk factors in comparison to the universal group. The smallest subset of families experiences elevated, intense, and/or escalating distress due to the presence of multiple risk factors and fall into the Clinical risk category.

Kazak et al[13,15] documented validity and reliability of the PAT and an empirical revision was consequently made to develop the PAT2.0 which demonstrated strong internal consistency ($\alpha = .81$).[10] Of note, psychosocial stress at the time of diagnosis was associated with higher levels of distress over time and social work utilization[15] and referrals for and/or utilization of psychosocial services.[16] The PAT2.0 was further revised by the scale developers to improve readability (to a third-grade reading level) and clarity, and this version was named the PAT_All-lit. The PAT_All-lit produces a Total Score (range of 0-7) and seven subscale scores (range of 0-1) that include: Family Structure and Resources, Caregiver Support, Child Problems, Sibling Problems, Caregiver Problems, Caregiver Stress Reactions, and Caregiver Beliefs. The Family Structure and

Resources subscale gathers information about the patient and caregiver's age, number of people living in the home, their ages, and their relation to the patient, insurance status, and financial stressors (ie, difficulty paying bills, transportation difficulties). The other subscales consist of multiple-choice formats.

The PAT has been used in many pediatric populations, including, but not limited to, transplant,[16] congenital heart disease,[17] pediatric inflammatory bowel disease,[18] headache,[19] and sickle cell disease.[20] The PAT has shown promise in feasibly allowing medical teams to quickly and effectively identify areas of psychosocial need, proactively disseminate psychosocial resources, and engage in routine monitoring. Moreover, the PAT has demonstrated high reliability and validity as a comprehensive screener; however it had yet to be used in CF care. The aims of this study were therefore to: (a) investigate the reliability (ie, internal consistency) of the PAT within this pediatric population, (b) describe the range and severity of psychosocial risk within this CF population, and (c) explore relationships between psychosocial risk and proxies for SES including parent education and insurance status. It was hypothesized that the PAT total and subscale α coefficients in this sample would be similar to those found in other pediatric medical populations.

2 | METHOD

2.1 | Participants

Caregivers of 154 children (<18 years of age) with a confirmed diagnosis of CF who received care at a midwestern Cystic Fibrosis Center completed the Psychosocial Assessment Tool_All-lit_Cystic Fibrosis (PAT-CF). Given only 6.4% of primary caregivers were not the child's parent, the term "parent" is used throughout the manuscript for simplicity. All parents spoke English and completed the PAT-CF in English. The PAT-CF was administered during routine clinical care and all participants in this study provided consent to have the information used for research purposes. Patients not included in our CF Center patient registry were excluded (ie, second opinions and international patients). There were no other exclusion criteria. Ten of the parents who completed the PAT-CF for clinical purposes declined research participation and are not included in the study sample.

2.2 | Measures

2.2.1 | PAT_All-lit_CF

For this study, CF-specific adaptations were made to the PAT_All-lit including removal of cancer-specific items or changing wording from "cancer" to "CF" when appropriate, and adding items to capture aspects of psychosocial risk for the CF population that were both clinically relevant and informed by the empirical research and is referred to as the PAT_All-lit_CF (PAT-CF). We made the following specific changes to the PAT2.0 to produce the PAT-CF version: (a) included new items such as use of Medicaid transportation to get to appointments, having additional state-based insurance coverage, and having an Individualized Education Program and/or 504 plan, (b) added two items to the Caregiver Stress scale ("Have you had any problems or concerns with your child following through on his/her medications, procedures, or treatment?" and "Have you had any problems or concerns with your child maintaining his/her eating, sleeping, or other daily routines?") and (c) added two items to the Caregiver Beliefs scale ("This diagnosis is hard for my child or family to accept" and "I must have done something wrong for my child to have this condition"). The purpose of adding the four items mentioned above was to screen for difficulties with adherence, following routines, and parent guilt. The PAT-CF used the same scoring as the original PAT2.0 other than the addition of the items to the Caregiver Stress and Caregiver Beliefs scales which were included in the scoring. The PAT-CF included 15 items and completion took about 10 minutes.

2.3 | Procedure

All parents completed the PAT-CF on an iPad, with the exception of two parents who completed the PAT-CF on paper. Registration staff administered tablets to families at check-in and social work-assisted parents with the sign in process if they were new to the assessment, or had difficulty signing in. Once parents completed the PAT-CF, an email with the results of the PAT was emailed securely to members of the psychosocial team (ie, social work and psychology) and one member of the psychosocial team reviewed results with the parent at the clinic visit. Clinical judgment was used to determine if information was best discussed at a later time without the child present (ie, parental substance use, caregiver relationship problems, and parent mental health). The study was approved by the institutional review board at the hospital where the study was conducted. Maximum missing data for all items comprising all PAT subscales ranged between 0.6% and 1.3% and was handled via the default categorical parameter estimation algorithm in Mplus (WLSMV; weighted least squares based on means and variances) version 7.4. Internal consistency reliability estimates for the PAT-CF total and subscale scores with item-level missing data were obtained using structural equation modeling techniques.[21] Spearman correlations were examined using SPSS version 24.

3 | RESULTS

3.1 | Sample characteristics

Parents who completed the PAT-CF had a mean age of 38 years (SD = 8.1). The majority of parents who completed the assessment were mothers (76%). The average age of the children that parents were reporting on was 8.6 years (SD = 5.1; range = 0-17) with 53.9% being girls. The sample included parents from diverse educational backgrounds and the majority reported having a home environment with more than one parent. Additional family demographics are summarized in Table 1.

TABLE 1 Demographics for study sample (n = 154)

Variable	n (%)/M(SD)
Caregiver	
Mother	118 (76.6)
Father	26 (16.9)
Grandparent	8 (5.2)
Other	2 (1.2)
Child sex (Female)	83 (53.9)
Parent ethnicity	
Caucasian	152 (98.7)
African American	2 (1.3)
Child ethnicity	
Caucasian	149 (96.8)
Biracial	3 (1.9)
African American	2 (1.3)
Caregiver marital status	
Married/Partnered	117 (76.0)
Single	22 (14.3)
Separated/Divorced	10 (6.5)
Other	5 (3.2)
Caregiver educational background	
Did not finish high school	11 (7.1)
Finished high school/GED	29 (18.8)
College courses or degrees	91 (59.1)
Some post-graduate education	18 (11.7)
Insurance status	
Insured	152 (98.7)
Private insurance	96 (62.3)
Medicaid	81 (51.9)
Multiple insurances	46 (29.9)
Additional state-based coverage	31 (20.1)
Uninsured	2 (1.3)

3.2 | Reliability

Internal consistency for the PAT-CF Total score was 0.71, see Table 2. All PAT-CF subscales had reliability coefficients equal or greater than 0.65, with several subscale reliabilities greater than 0.85.

3.3 | Risk classification

Total PAT-CF scores classified families' level of psychosocial risk. The majority of families were classified into the Universal risk classification (52%) with 41% classified into the Targeted risk category. The remaining 7% of families were classified in the most at risk classification, Clinical. See Table 3 for sample demographics.

Clinically, a subscale score of over 0.5 indicates that a family may be at risk in that specific psychosocial area. In this sample, limited social support was a risk factor for 14.4%. Caregiver and family concerns were identified as a specific risk factor in 13.1% of the sample. Child problems indicated psychosocial risk in 9.2% and sibling concerns were an identified risk factor in 7.4% of the sample. Approximately 6% were at psychosocial risk based on family structure (ie, single-parent home or having multiple young children in the home). Caregiver stress reactions to the child being sick or being in the hospital were infrequently reported (1.3%) and negative family beliefs were identified as a risk factor for less than 1% of parents. Responses for the sample are detailed in Table 3.

3.4 | Variables associated with psychosocial risk

In line with Aim 3, we examined associations between PAT-CF total risk score and demographic variables, including SES proxies using Spearman correlations. Total risk score was negatively associated with parent education, $r = -0.252$, $P = .002$. Medicaid status was associated with increased psychosocial risk, $r = 0.327$, $P < .001$ and lower parent education, $r = -0.342$, $P < .001$, whereas having private insurance was associated with decreased psychosocial risk, $r = -0.281$, $P = .001$ and higher parent education, $r = 0.315$, $P < .001$. We further examined the relationships between the PAT-CF Family Structure/Resources subscale, parent education and insurance status. Higher risk on this subscale reflected a single-parent household, parents not finishing school, needing rides to clinic appointments, and/or endorsing significant and multiple financial problems that made it difficult to meet basic needs. We found that increased risk on this PAT subscale was associated with lower parent education, $r = -0.380$, $P < .001$, Medicaid status, $r = 0.398$, $P < .001$ and not having access to private insurance, $r = -0.415$, $P < .001$. The Family Structure/Resources subscale also demonstrated a strong correlation with overall PAT-CF risk, $r = 0.560$, $P < .001$.

4 | DISCUSSION

This is the first study to describe the range and intensity of comprehensive psychosocial risk in pediatric CF using an empirically-based measure and to report on the psychometric properties of the PAT-CF. This tool allows for systematic screening to identify a broad range of individual, family, financial, and social domains that can impact care and outcomes to guide the provision of appropriate education and services to patients with CF and their families.

TABLE 2 Descriptive statistics and internal consistency for PAT-CF All-Lit Total score and subscales

PAT-CF All-Lit scale items	Range	M	SD	Internal consistency
Total	0-3.30	1.0	0.70	0.71
Structure/Resources	0-0.63	0.16	0.16	0.65
Social support	0-1.0	0.12	0.22	0.89
Child problems	0-0.87	0.25	0.19	0.85
Sibling problems	0-0.94	0.16	0.20	0.94
Caregiver problems	0-1.0	0.23	0.21	0.87
Caregiver stress reactions	0-0.60	0.06	0.10	0.74
Family beliefs	0-0.63	0.05	0.10	0.71

Note: Internal consistency reliability estimates calculated based on approach described by Geldhof et al.[21]

Abbreviation: PAT-CF, Psychosocial Assessment Tool_All-lit_Cystic Fibrosis.

TABLE 3 Psychosocial characteristics from PAT-CF caregiver responses

Category				
Risk classification	n (%)			
Universal (Total score, 0 to <1.0)	80 (51.9)			
Targeted (Total score, 1.0 to <2.0)	63 (40.9)			
Clinical (Total score, ≥2.0)	11 (7.2)			
Caregiver stress	*None*	*Sometimes*	*Often*	*Very much*
Bad dreams about child being sick	86 (55.8)	65 (42.2)	3 (2.0)	0 (0.0)
Feeling jumpy coming to the hospital	113 (73.9)	36 (23.5)	1 (0.7)	3 (1.9)
Sweating or shaking about child being sick	101 (65.6)	40 (26.0)	6 (3.9)	7 (4.5)
Trouble following CF daily regimen	84 (54.5)	61 (39.6)	8 (5.2)	1 (0.7)
Trouble with eating, sleeping, or routine	78 (50.6)	62 (40.3)	9 (5.8)	5 (3.3)
Caregiver beliefs	*Not true*	*A little true*	*Mostly true*	*Very true*
Medical team will know what to do	5 (3.3)	4 (2.6)	39 (25.5)	105 (68.6)
Our family will be closer because of CF	19 (12.4)	28 (18.3)	64 (41.8)	42 (27.5)
Our marriage or family will fall apart	129 (84.3)	16 (10.5)	4 (2.6)	4 (2.6)
The diagnosis is hard to accept	84 (54.9)	58 (37.9)	9 (5.9)	2 (1.3)
We can make good treatment decisions	4 (2.6)	3 (1.9)	33 (21.6)	113 (73.9)
We're going to beat this	6 (4.0)	19 (12.5)	42 (27.6)	85 (55.9)
Caregiver problems	*Yes*			
A lot of worry, fear, or anxiety	86 (55.8)			
Problems with drugs/alcohol	13 (8.4)			
Sad or depressed	84 (54.5)			
Problems with attention, focus, concentration	39 (25.3)			
Relationship problems	32 (20.8)			
Drinking too much alcohol	7 (4.5)			
Child problems	*Yes*			
A lot of worry, fear, or anxiety	49 (31.8)			
Sad or depressed	16 (10.4)			
Problems with attention, focus, concentration	67 (43.5)			
Sibling problems	*Yes*			
A lot of worry, fear, or anxiety	35 (27.8)			
Sad or depressed	12 (9.5)			
Problems with attention, focus, concentration	36 (28.6)			
Family resources	*Yes*			
Difficulty with transportation	15 (10.2)			
Financial troubles	16 (10.9)			
Part of a faith-based or spiritual group (*Yes*)	95 (61.7)			

Note: Psychosocial Assessment Tool 2.0 items are included in Pai et al.[10]
Abbreviation: PAT-CF, Psychosocial Assessment Tool_All-lit_Cystic Fibrosis.

Overall, excellent to acceptable reliability was observed for Total and subscale scores on the PAT-CF, with the exception of the Family Resources subscale. Generally, the psychometrics reported for this sample are comparable to those reported by others.[10,20,22,23] The Family Resources subscale's questionable reliability value seen in this sample is similarly low in pediatric cancer and sickle cell samples.[10,20] The overall consistency in psychometric properties across disease populations supports the generalizability and utility of the PAT-CF in this population.

The majority of our sample fell in the Universal risk range, indicating the need for anticipatory guidance and supportive strategies to promote wellness, positive family functioning, and sustaining daily care as a first line intervention for many families. More than 30% of our sample was in the Targeted risk range highlighting the need for increased support and targeted intervention at point-of-care to address areas of elevated psychosocial risk. Parents of 7% of the sample reported risk in the Clinical range, indicating the need for more intensive, varied types of support matched to need, access to effective family-based interventions to promote treatment adherence, and closer follow up. The distribution of risk stratification in our sample was similar to what was observed in published cancer, sickle cell, and gastrointestina (GI) populations for the Universal and Targeted risk categories, 50% to 64% and 32% to 36%, respectively. We had a decreased percentage of families falling in the Clinical range however (7%) relative the other samples (0%-14%).[10,16,24]

In our sample a higher total risk score was associated with lower parent education and Medicaid status. Oates and Schechter[25] called for greater attention to be paid to parent education, SES markers, and social support to improve health outcomes. In this sample, 7% of parents had not completed high school. Almost 21% of parents endorsed experiencing relationship problems with the adults in the

home including fights and talk of separation or divorce, with nearly 20% reported being "single" or "separated/divorced". Understanding family functioning is important as sharing the burden of managing a chronic illness with family members or another person outside of the family can serve as an effective coping strategy, as well as decrease family vulnerability to stress.[26-28]

Though the screening information is not diagnostic in nature, approximately 56% of parents reported experiencing "a lot of worry, fear, and anxiety" as well as feeling "sad or depressed". Slightly more than 8% of parents reported the occurrence of problematic drug or alcohol use for an adult in the home. Parents of 32% of children reported that their children experienced "a lot of worry, fear, and anxiety", with slightly less for siblings (28%). Child problems with attention, focus, and concentration were also frequently reported (44%). Notably, parent responses also reflected hope and resilience. Specifically, parents reported believing in the medical team's knowledge, having more cohesive families due to having CF, acceptance of the CF diagnosis, and that they could make "good" treatment decisions. Nearly 84% of the sample reported that it was "mostly or very true" that they were going to "beat CF". The PAT-CF therefore elicited valuable information from families reflective of risk and protective factors.

Use of the PAT-CF has several positive implications for enhancing psychosocial care in CF. First, it is a brief standardized tool that can be feasibly completed and reviewed in clinic which allows for early identification of psychosocial risk factors within family systems, including sibling functioning which often receives limited attention in routine CF care. Use of the PAT-CF in an electronic format allowed for real-time scoring and point-of-care use of results from the assessment. Next, identifying risk factors within an interdisciplinary context can promote efficient delivery of team-based psychosocially informed clinical care, enhance relationships with families, and decrease the stigma associated with many of these psychosocial challenges. Our data support families' willingness to complete a screener and discuss psychosocial risk factors in the context of CF clinical care and the PAT-CF's utility in developing and delivering targeted empirically supported psychoeducation, interventions, and referrals. The PAT-CF is therefore a feasible and valuable tool to guide the annual CF social work assessment, and in fact is the standard assessment for social work at our Center. Finally, the PAT-CF Total score can be used to stratify families according to psychosocial risk, akin to medical stratification of nutrition and lung function risk. This "at a glance" categorization can quickly provide valuable context to all CF team members and subsequently inform and enhance their provision of care.

5 | LIMITATIONS

Limitations of this study include the sample being nested within one pediatric CF Center which may limit generalizability. Our sample's racial distribution closely aligns with the most recent CFF patient registry data, with nearly 97% identifying as white (93.7% in the registry), slightly less (1.3%) identifying as African American (4.6% in registry), and 1.9% biracial compared to 3.5% "other" in the registry.[29] In addition, a slightly smaller percentage of our sample had a two-caregiver household (76%) compared to cancer and pediatric GI populations.[16,18] And while we do not have first-language Spanish-speaking families in this clinic sample, the PAT has been adapted in Spanish and initial use of the Spanish version in pediatric cancer found that more families fell in the Clinical and Targeted groups, reflecting increased psychosocial risk in need of attention for this ethnic minority group.[30]

Although our sample risk stratification aligned closely with other disease populations, it is possible that parents may have underreported risk due to the influence of social desirability. The Family Resources subscale of the PAT-CF demonstrated questionable reliability yet provides important clinical information and should be retained in the scale to calculate total risk. Given the pilot nature of this study, future research should examine repeated measure administration and association between PAT-CF scores with other key variables over time, including medical outcomes and utilization of psychosocial resources. Moreover, use of the PAT with a larger population, including CF Centers with more diverse ethnic representation will be an important next step to examine how the screener functions. Finally, correlational findings do not allow for causal conclusions to be drawn yet draw attention to important associations worthy of ongoing attention.

6 | CONCLUSION

Results indicate that the PAT-CF is a reliable assessment of psychosocial risk categories in families of children with CF. Further, findings from the current study demonstrate that parents are willing to report psychosocial risks that exist within the family system and call for increased real-time systematic assessment of comprehensive psychosocial risk to respond with the appropriate resources and interventions as proactively as possible. In the last several years the CF care model has evolved to include routine screening for anxiety and depression for patients and caregivers. As CF teams, and patients and families, become more comfortable and skilled at discussing and attending to the emotional and behavioral factors that impact daily functioning, other factors can be screened for to achieve a more comprehensive approach to whole-person care. The PAT-CF's broad scope, real-time scoring capabilities, and potential application to an annual psychosocial assessment render it an ideal screener for clinical consideration, and has been further revised and updated recently.[31] Akin to the efforts to systematize assessment of CF physical symptoms and use clinical algorithms to provide improved, efficient, and cost-effective medical care for children and families, a comprehensive evidence-based assessment such as the PAT can guide a similar approach to identifying and responding to psychosocial factors to promote better outcomes.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

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