



# Identifying and Integrating Parent Priorities for Psychosocial Support Services in a Pediatric Cystic Fibrosis Clinic

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## Abstract

Engaging parents early in the development of psychosocial support programs in cystic fibrosis (CF) clinics may enable services and care team recommendations to be tailored appropriately. This pilot study identified psychosocial priorities of parents of children with CF related to treatment adherence, parent/child mental health, and CF-related communication. Forty parents of children with CF (2 months to 17 years) completed an anonymous 17-item survey during routine clinic visits that assessed priorities related to psychosocial services. Elements of a quality improvement framework were used to develop the survey and determine recommendations based on findings. Parents reported the most interest in support related to improving adherence to respiratory therapies and helping children complete treatments independently. Other priority areas included services that helped children cope with feelings of isolation or abnormality due to CF and strategies to improve communication with the care team. Additionally, the majority of families indicated that they preferred receiving psychosocial services during routine clinic visits, followed by periodic parent workshops. Based on survey results, the psychosocial team at our center developed a survey/response model (e.g., roundtables, workshops) that may serve useful for other CF care teams as they identify the priorities of parents and adapt to their needs.

**Keywords** Cystic fibrosis · Children · Psychosocial priorities · Adherence · Families

Cystic fibrosis (CF) is a progressive, genetic disease that causes digestive abnormalities and a buildup of mucus in the lungs, and requires daily treatment to minimize respiratory infection complications and ensure the absorption of nutrients (Elborn, 2016). Historically, most patients with CF (> 75%) are diagnosed in the first year of life, which has increased with acceptance of newborn screening for CF. Given recent advancements in CF care, median life expectancy is about 40 years (Cystic Fibrosis Foundation [CFF], 2017). On average, optimal adherence to CF treatment takes several hours a day and may include airway clearance therapies, pancreatic enzyme supplements, antibiotics, and inhaled medications (Sawicki, Sellers, & Robinson, 2009). Parents and family members play a significant role in ensuring patient adherence (DeLambo, Ievers-Landis, Drotar, &

Quittner, 2004). Physicians treating patients with CF have identified nonadherence as a prominent barrier to best care practices, although these potential barriers are not consistently discussed with families (Glauser et al., 2012). In fact, a recent report found that only 64% of CF centers discussed adherence with patients at every clinic visit (Riekert, Eakin, Bilderback, Ridge, & Marshall, 2015). Low levels of adherence to daily treatment regimens have been linked to factors such as poor family functioning, child oppositional behaviors, and lack of time (Everhart, Fiese, Smyth, Borschuk, & Anbar, 2014; Modi & Quittner, 2006).

Given that mental health and communication challenges have been identified as barriers to optimal disease self-management, they were the focus of our survey for this pilot study. For instance, reports suggest that CF patients and their parents experience elevated rates of depression and anxiety (Quittner et al., 2014), which can adversely impact treatment adherence. Mental health difficulties may compromise parental involvement and supervision of treatments, increase parent-child conflict, and reduce belief in the efficacy of CF treatments (Barker, Driscoll, Modi, Light, & Quittner, 2012; Hilliard, Eakin, Borrelli, Green, & Riekert, 2015; Smith,

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Modi, Quittner, & Wood, 2010). The CFF has recognized the link between mental health and adherence behaviors as an important area for intervention and improvement in CF care. Routine screening of anxiety and depressive symptoms for patients and parents has, therefore, become a point of emphasis for psychosocial care teams as evidenced by the recent CFF guidelines (Quittner et al., 2015).

In addition to attention to adherence and mental health difficulties, families of children with CF may also benefit from psychosocial support focused on effective communication with others and within families about CF (Quittner, Saez-Flores, & Barton, 2016). Recent research suggests that adolescents who do not disclose their CF to others are often less compliant with treatments (Borschuk et al., 2016). Patient concerns about being stigmatized or socially isolated by peers for having CF have been associated with lower lung function (Oliver et al., 2014). Parental discussions with children about life expectancy or describing CF to peers or teachers may also necessitate additional support from care teams.

To date, however, studies have not identified the specific psychosocial services that parents would prioritize for their child's care. Qualitative interviews and care surveys have identified barriers to disease self-management in adolescents with CF and their parents, such as time pressures, competing priorities, and lack of perceived consequences from nonadherence (Homa, Sabadosa, Nelson, Rogers, & Marshall, 2013; Sawicki, Heller, Demars, & Robinson, 2015). However, these studies have not considered the psychosocial support interests of parents; engaging parents early in the development of psychosocial support service programs in CF clinics may enable services and recommendations from psychologists and other care team members to be tailored appropriately. Moreover, matching psychosocial services with parent treatment preferences (e.g., treatment targets, delivery format) increases the likelihood of service use and engagement (Bannon Jr & McKay, 2005; Morrissey-Kane & Prinz, 1999).

Available psychosocial services in CF clinics can cover a range of topics including issues related to treatment adherence, parent and/or child mental health, and CF-related communication. The diversity in psychosocial needs, however, can make it challenging for care teams to identify the most pressing issues for each family and tailor their recommendations accordingly. In the current study, we used components of a quality improvement (QI) framework (Langley et al., 2009) to improve the efficacy of psychosocial services delivered within our CF clinic. We incorporated elements of the Plan-Do-Study-Act framework of QI projects in the development of our survey and in determining recommendations based on these findings. Specifically, this pilot study engaged parent stakeholders to identify their priorities related to psychosocial care (e.g., treatment adherence,

mental health, communication) through a clinic-wide survey. We also describe practice implications for psychologists and other members of the CF care team based upon parent priorities.

## Methods

Forty parents of children with CF between 2 months and 17 years completed a survey assessing their priorities related to psychosocial services as part of a pilot study. The survey was administered anonymously to English-speaking parents of children seen at the Children's Hospital of Richmond at VCU from January to May 2017 for an outpatient CF clinic visit. Our clinic follows 48 CF patients between the ages of 2 months and 17 years. All eligible parents seen at the clinic from January to May 2017 ( $n = 40$ ) agreed to complete our survey. Therefore, the majority (83%) of families seen at our clinic completed this survey. Eight parents did not complete the survey: three were not English-speaking, two were not seen during the study period, and three completed the survey once as parents of sibling patients. Thus, five parents were not approached to complete the survey (i.e., not English-speaking or not seen during study period).

## Quality Improvement Framework

We used aspects of QI methodology in identifying parent priorities and determining action based on our findings (Ewins, Macpherson, van der Linden, & Arnott, 2017; Langley et al., 2009). In line with the Plan phase, initial survey items were developed based upon the psychosocial team's clinical interactions with families and existing literature on the psychological burden of CF. Expert review from the full clinic care team (i.e., social worker, pulmonologists, respiratory therapists, registered dietician, and nursing) was used to refine survey items. In the Do phase, the developed survey was then administered to parents of children with CF who met our eligibility criteria. In the Study phase, survey results were reviewed to inform changes to our current psychosocial services. Finally, in the Act phase, we describe how our psychosocial services were modified and tailored based on the results of the survey, as well as provide recommendations for other care teams to improve the delivery of their psychosocial services.

## Psychosocial Service Priorities Survey

The 17-item survey was developed by our psychosocial team (i.e., pediatric psychologist, clinical psychology practicum student) and was part of a larger QI initiative to improve the efficacy of psychosocial services provided by the clinic. Sixteen items addressed three major areas of

services: treatment adherence, parent/child mental health, and CF-related communication. Parents were asked to rate their interest level (not interested, slightly interested, interested, very interested) in receiving services from the CF care team related to each item. A final item asked parents how they would prefer to receive services from the team (during clinic visits, periodic workshops/support groups, regular sessions outside of clinic). Parents indicated all formats in which they were interested.

**Table 1** Patient characteristics ( $n = 40$ )

	<i>n</i> (%)
Age, <i>M</i> ( <i>SD</i> ) years	10.56 (5.18)
Male	23 (57.5)
White	33 (82.5)
African American	6 (15)
Latino	1 (2.5)
Medicaid as primary or supplementary insurance	18 (45)

**Table 2** Parent interest in psychosocial services at pediatric cystic fibrosis clinic

Item	<i>M</i> ( <i>SD</i> )	Not at all interested (0); <i>n</i> (%)	Slightly interested (1); <i>n</i> (%)	Interested (2); <i>n</i> (%)	Very interested (3); <i>n</i> (%)
<b>Adherence</b>					
Improving my child's adherence to respiratory (breathing) treatments	1.63 (1.10)	9 (23)	7 (18)	14 (35)	10 (25)
Helping my child independently complete daily treatments	1.58 (1.11)	10 (25)	6 (15)	15 (38)	9 (22)
Improving my child's adherence to weight management	1.20 (1.07)	14 (35)	9 (23)	12 (30)	5 (12)
Improving my child's pill swallowing behavior	0.53 (1.06)	31 (78)	2 (5)	2 (5)	5 (12)
<b>Mental health</b>					
Helping my child cope with feelings of isolation or of being different from peers because of his/her CF	1.15 (1.06)	15 (38)	7 (18)	13 (33)	4 (10)
Managing my child's overall stress	1.08 (0.89)	12 (30)	15 (38)	11 (27)	2 (5)
Managing my child's mood or anxiety	1.03 (1.03)	17 (43)	8 (20)	12 (30)	3 (7)
Managing my own mood or anxiety	0.98 (1.07)	19 (47)	7 (18)	10 (25)	4 (10)
Managing my child's disruptive behavior (e.g., tantrums, defiance)	0.95 (1.15)	21 (52)	6 (15)	7 (18)	6 (15)
Managing my own overall stress	0.93 (1.05)	19 (47)	9 (23)	8 (20)	4 (10)
Managing my child's concerns about his/her body image	0.43 (0.81)	29 (72)	7 (18)	2 (5)	2 (5)
<b>Communication</b>					
Communicating effectively with the CF care team about my child's treatment/functioning	1.46 (1.02)	9 (23)	9 (23)	15 (38)	6 (15)
Improving communication with my child about his/her CF	1.28 (1.06)	13 (33)	8 (20)	14 (35)	5 (12)
Communicating with others (friends/family, teachers, co-workers) about CF	1.28 (1.10)	13 (33)	8 (21)	12 (31)	6 (15)
Improving communication with my child about issues specifically related to CF life expectancy	1.15 (1.01)	13 (33)	11 (28)	11 (28)	4 (10)
Improving communication with my child about his/her daily life (e.g., school, friends)	1.13 (1.03)	14 (36)	10 (26)	2 (28)	4 (10)

CF cystic fibrosis

## Results

Demographics of surveyed patients are presented in Table 1. Our sample was primarily White (82.5%) and 45% of patients were on Medicaid either as primary or supplementary insurance. The mean of each psychosocial survey item and the frequency of parents endorsing each response are presented in Table 2.

Survey responses indicated that families had a diverse set of psychosocial priorities, with at least 30% of parents expressing significant interest in 14 of the 16 topics. When comparing specific items, parents were most interested in improving respiratory therapy adherence (60% rated “interested” or “very interested”) and helping patients complete treatments independently (60% rated “interested” or “very interested”). Regarding communication, parents were most interested in developing strategies to improve communication with the care team (53% rated “interested” or “very interested”). Of note, a similar percentage of parents reported being “not at all interested” (33%) and “interested” (35%) in improving communication with their child about

CF; this trend was also found among parents reporting “not at all interested” (33%) and “interested” (31%) in improving communication with others about CF. Within the mental health domain, 43% of parents reported being “interested” or “very interested” in services that helped children cope with feelings of isolation or abnormality due to CF. When also taking into account the rating of “slightly interested,” 70% of parents reported at least some interest in managing their child’s overall stress (ratings of “slightly interested,” “interested,” or “very interested”); similarly, 57% of parents expressed at least some interest in managing their child’s mood or anxiety.

Several topics had low overall interest, but were of high importance to a limited number of parents. For example, pill swallowing was of no interest to 78% of parents, but 12% indicated being “very interested.” Similarly, nearly one-third of all parents endorsing any concerns about managing their child’s disruptive behavior responded that they were “very interested” in receiving support on the topic. Other topics had a sizeable number of families express lower levels of interest. For example, body image was a topic of interest to 28% of parents, although they primarily endorsed being “slightly interested.”

Responses to the delivery format item indicated that a majority of families (54%) were interested in receiving services in the clinic room as part of a routine clinic visit. A smaller number of families (18%) expressed a desire to receive psychosocial services in a separate room during the clinic visit. A number of families also expressed interest in receiving services outside of their routine clinic visits; 36% of respondents indicated they were interested in periodic workshops for parents, and 21% endorsed interest in weekly meetings outside of clinic visits.

## Discussion

This pilot study engaged parents of children with CF in setting the agenda for psychosocial support within clinics by identifying their preferences and priorities. Our findings suggest that parents were open to receiving adherence support from the care team, especially as it related to helping children independently complete treatments. Adolescence has been noted as a developmental period in which adherence declines, often due to decreased parental monitoring and increased responsibility for the adolescent (Bishay & Sawicki, 2016). Thus, parents in our sample may have been indicating a desire for their adolescent to manage CF without parental assistance. It may also be that parents found it difficult to match their children’s role in care with their cognitive and developmental abilities. Thus, parents of younger children in our study may have been expecting their children to be more independent based on misunderstanding

the developmental needs and abilities of children and adolescents. Because our survey was anonymous, we were not able to directly link child age with parent responses. Regardless, we recommend that care teams recognize that adherence continues to be a high priority area for parents, and discussions regarding patients independently managing their treatments may be necessary.

Although parents did not prioritize services related to mental health and communication as highly as adherence, mental health and communication were still of interest to many families. It is also important to recognize that these issues often contribute to nonadherence. Helping children cope with social factors (e.g., feelings of isolation) and manage their mood/anxiety drew the most interest from parents. Further, parents frequently reported interest in improving communication with the care team, which is consistent with existing literature detailing issues that can affect adherence (Quittner et al., 2016). Given that parents prioritized adherence, care teams may need to frame discussions about mental health and communication within the context of adherence. For example, psychosocial teams may provide strategies for communicating more effectively as a way to improve daily adherence. Doing so may increase parent interest in discussing issues that are less prioritized, but equally important in CF adherence behaviors. Interestingly, findings regarding improving communication with their children about CF were mixed in that similar percentages of parents endorsed being “interested” and “not at all interested” in this topic. Future research is needed to determine under what circumstances parents desire to improve communication with their children and, subsequently, how best to support parents in these conversations.

Findings also suggested several services of high importance for a limited number of parents, including pill swallowing, managing child disruptive behaviors, and body image concerns. These topics generated “all-or-none” response patterns, with parents expressing either no interest or very high interest. In maintaining a QI focus, we have begun to ask parents directly about these issues that may be less frequent, but of equal importance. We suggest that other care teams ask parents directly about these issues, especially as they may be barriers to adherence. Parents may not bring up these issues frequently, but when such issues do arise, it appears that parents may be interested in receiving services. Thus, care teams may need to have protocols in place to address pill swallowing and strategies for managing externalizing behaviors and body image concerns.

With respect to delivery format, we found that parents most preferred receiving psychosocial services as a part of their routine clinic visit. Parents may find that this option reduces the burden related to attending a separate appointment and allows service delivery to the family as a whole. A follow-up question regarding whether parents

would be willing to extend their clinic visit to accommodate such services is needed in the next iteration of this survey. Additionally, a third of parents surveyed indicated interest in periodic workshops. Group workshops may allow parents to receive benefits from both the psychosocial team and from the support and experiences of other parents.

### Limitations

Given that this was a pilot study with 40 families, replication is needed with a larger sample of parents from multiple centers to determine generalizability of the findings. Parents also completed this survey anonymously, and it was not possible to link parent priorities to child demographics, such as age or gender. It is likely that issues related to body image or mood may be more relevant for parents of adolescents, whereas issues related to oppositional behaviors may be priorities for parents of younger children. We suggest that future studies consider parent priorities by child age and aim to make recommendations for tailoring services specifically by child age. Moreover, this study did not inquire about patient preferences for psychosocial services. Researchers may wish to expand this survey to a self-report version for adolescents that would allow them to report on their own priorities, which may differ from those of their parents. This would allow centers to tailor psychosocial services to meet adolescent priorities as well, which may include the integration of family-based services for similar parent and adolescent priorities. On the other hand, and depending upon topics areas, different services may be needed to individually address parent and adolescent priorities and especially conflict within families regarding differences in priorities. We acknowledge that our survey items may have missed other priority areas, such as interest in services related to support around other areas of adherence (e.g., oral medications). Given our limited sample size, we were not able to determine whether differences in the percentages of parents endorsing each response option were statistically significant. Finally, although we incorporated aspects of a QI framework in our study, we recognize that QI is an ongoing process. We suggest that future QI projects evaluate whether changes in the way psychosocial services are delivered to patients and parents based on this survey are beneficial and effectively implemented. This may include follow-up surveys to determine the acceptability of such services, whether patients and parents believed that the services had met their needs, and what changes they had seen in these areas (i.e., an improvement in communication with the care team) based on these services delivered within the clinic.

### Clinical Implications

This study highlights a topic of interest among providers: integrating behavioral health services in medical settings. Using parent stakeholder feedback, we have begun a process of program development for integrating psychosocial support services into our pediatric CF center that matches the priorities of our families. Based on survey results from this pilot study, the psychosocial team at our center presented a roundtable focused on treatment adherence and communication skills at a family education seminar. We also developed a small workshop series for parents at our center that addresses the range of topics identified from our survey. For example, our first 2-h workshop addressed the association between CF disclosure and adherence, strategies for managing child and parent stress, and talking with children about challenging issues, such as life expectancy. The workshop format allowed parents to interact with one another and learn how other parents had discussed CF with their children. This survey/response model serves as a template for other CF care teams as they identify the psychosocial priorities of parents and adapt to meet their needs. In fact, other CF care centers may wish to use or adapt our survey to identify the psychosocial needs of the parents of their patients. Results of such surveys may allow care teams to begin tailoring their psychosocial services to meet the priority areas identified at their sites and to better meet the needs of patients.

Additionally, in improving our psychosocial services, we have begun to incorporate frequent education into routine clinic visits given that over half of our sample indicated interest in receiving services as part of their clinic visit. We provide general education to families that is focused on behavioral strategies for increasing adherence to enzymes or airway clearance in younger children, strategies for CF disclosure in new school or work settings, and navigating increased patient responsibilities in CF care. Education regarding parent self-care and managing both parent and child stress or anxiety are also provided when families voice a particular need for such information through discussions with the psychosocial team. We suggest that other care teams aim to integrate both general and more specific education based on family needs into routine clinic visits. Although time for education is limited in clinic visits, families may benefit from receiving brief education that relates to the priority areas identified in this study, including adherence to respiratory therapies and helping children complete treatments independently.

### Future Directions

The diversity of psychosocial needs for patients with CF also suggests the need for future research to establish valid, individual-oriented clinical assessment tools.

Although our clinic-wide survey highlights the domains of psychosocial support that draw the most interest from patients and families on average, it provides limited insight into the specific needs of an individual family. Given the heterogeneity of families' psychosocial needs and the consideration that psychosocial support is most frequently administered in a one-on-one format, a one-size-fits-all approach to psychosocial support for CF patients may not be reasonable (Riekert et al., 2015). Therefore, clinical interviews or rating scales that assess individual families' needs for psychosocial support related to treatment adherence, general mental health, and CF-related communication could help care teams provide more personalized psychosocial support to each patient. One potential solution is to further examine the psychometric properties of our survey and determine whether it could be readily adapted into a brief rating scale that provides useful individual-level data. Alternatively, a clinical interview that guides a more in-depth conversation between care teams and families about their need for support along the broad domains assessed in this survey could provide care teams with more specific information to further aid in the personalization of psychosocial services.

In addition to using this survey as a launching point for the development of new clinical assessment tools, we also suggest that researchers and clinicians consider using this model to develop surveys to identify the psychosocial priorities of other chronic illness populations, both pediatric and adult. Treatment adherence, mental health, and health-related communication are all relevant domains for the management of nearly all chronic conditions. However, the specific needs and intensity of support within these domains will likely differ from the needs of patients with CF. Thus, the framework of this study has potential applicability for providers and care teams treating a range of chronic conditions. We suggest that researchers and healthcare providers use the results of this pilot study to identify effective ways to recognize and address the psychosocial priorities of their patients, which will ultimately serve to improve the overall well-being and health of patients.

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### Compliance with Ethical Standards

**Conflict of interest** The authors Robin S. Everhart, Stephen J. Molitor, Dena Wentz, H. Joel Schmidt, and Michael S. Schechter declare that they have no conflict of interest.

**Human and Animal Rights** All procedures were in accordance with the ethical standards of the institutional research committees and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

### References

- Bannon, W., Jr., & McKay, M. (2005). Are barriers to service and parental preferences match for services related to urban child mental health service use? *Families in Society: The Journal of Contemporary Social Services*, 86, 30–34.
- Barker, D. H., Driscoll, K. A., Modi, A. C., Light, M. J., & Quittner, A. L. (2012). Supporting cystic fibrosis disease management during adolescence: The role of family and friends. *Child: Care, Health, and Development*, 38, 497–504.
- Bishay, L. C., & Sawicki, G. S. (2016). Strategies to optimize treatment adherence in adolescent patients with cystic fibrosis. *Adolescent Health, Medicine, and Therapeutics*, 7, 117–124.
- Borschuk, A. P., Everhart, R. S., Eakin, M. N., Rand-Giovannetti, D., Borrelli, B., & Riekert, K. A. (2016). Disease disclosure in individuals with cystic fibrosis: Association with psychosocial and health outcomes. *Journal of Cystic Fibrosis*, 15, 696–702.
- Cystic Fibrosis Foundation. (2017). *About cystic fibrosis*. Retrieved from <https://www.cff.org/What-is-CF/About-Cystic-Fibrosis/>. Accessed 10 May 2017.
- DeLambo, K. E., Ievers-Landis, C. E., Drotar, D., & Quittner, A. L. (2004). Association of observed family relationship quality and problem-solving skills with treatment adherence in older children and adolescents with cystic fibrosis. *Journal of Pediatric Psychology*, 29, 343–353.
- Elborn, S. (2016). Cystic fibrosis. *Lancet*, 338, 2519–2531.
- Everhart, R. S., Fiese, B. H., Smyth, J. M., Borschuk, A., & Anbar, R. D. (2014). Family functioning and treatment adherence in children and adolescents with cystic fibrosis. *Pediatric Allergy, Immunology, and Pulmonology*, 27, 82–86.
- Ewins, E., Macpherson, R., van der Linden, G., & Arnott, S. (2017). Training in quality improvement for the next generation of psychiatrists. *BJPsych Bulletin*, 41, 45–50.
- Glauser, T. A., Nevins, P. H., Williamson, J. C., Abdolrasulnia, M., Salinas, G. D., Zhang, J., ... Riekert, K. A. (2012). Adherence to the 2007 cystic fibrosis pulmonary guidelines: A national survey of CF care centers. *Pediatric Pulmonology*, 47, 434–440.
- Hilliard, M. E., Eakin, M. N., Borrelli, B., Green, A., & Riekert, K. A. (2015). Medication beliefs mediate between depressive symptoms and medication adherence in cystic fibrosis. *Health Psychology*, 34, 496–504.
- Homa, K., Sabadosa, K. A., Nelson, E. C., Rogers, W. H., & Marshall, B. C. (2013). Development and validation of a cystic fibrosis patient and family member experience of care survey. *Quality Management in Health Care*, 22, 100–116.
- Langley, G. L., Moen, R., Nolan, K. M., Nolan, T. W., Norman, C. L., & Provost, L. P. (2009). *The improvement guide: A practical approach to enhancing organizational performance* (2nd ed.). San Francisco: Jossey-Bass.
- Modi, A. C., & Quittner, A. L. (2006). Barriers to treatment adherence for children with cystic fibrosis and asthma: What gets in the way? *Journal of Pediatric Psychology*, 31, 846–858.
- Morrissey-Kane, E., & Prinz, R. J. (1999). Engagement in child and adolescent treatment: The role of parental cognitions and attributions. *Clinical Child and Family Psychology Review*, 2, 183–198.
- Oliver, K. N., Free, M. L., Bok, C., McCoy, K. S., Lemanek, K. L., & Emery, C. F. (2014). Stigma and optimism in adolescents and young adults with cystic fibrosis. *Journal of Cystic Fibrosis*, 13, 737–744.

- Quittner, A., Abbott, J., Georgiopoulos, A., Goldbeck, L., Smith, B., Hempstead, S., ... Elborn, S. (2015). International committee on mental health in cystic fibrosis: Cystic fibrosis foundation and European cystic fibrosis society consensus statements for screening and treating depression and anxiety. *Thorax*, *71*, 26–34.
- Quittner, A. L., Goldbeck, L., Abbott, J., Duff, A., Lambrecht, P., Solé, A., ... Catastini, P. (2014). Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: Results of The International Depression Epidemiological Study across nine countries. *Thorax*, *69*, 1090–1097.
- Quittner, A. L., Saez-Flores, E., & Barton, J. D. (2016). The psychological burden of cystic fibrosis. *Current Opinion in Pulmonary Medicine*, *22*, 187–191.
- Riekert, K. A., Eakin, M. N., Bilderback, A., Ridge, A. K., & Marshall, B. C. (2015). Opportunities for cystic fibrosis care teams to support treatment adherence. *Journal of Cystic Fibrosis*, *14*, 142–148.
- Sawicki, G. S., Heller, K. S., Demars, N., & Robinson, W. M. (2015). Motivating adherence among adolescents with cystic fibrosis: Youth and parent perspectives. *Pediatric Pulmonology*, *50*, 127–136.
- Sawicki, G. S., Sellers, D. E., & Robinson, W. M. (2009). High treatment burden in adults with CF: Challenges to disease self-management. *Journal of Cystic Fibrosis*, *8*, 91–96.
- Smith, B. A., Modi, A. C., Quittner, A. L., & Wood, B. L. (2010). Depressive symptoms in children with cystic fibrosis and parents and its effects on adherence to airway clearance. *Pediatric Pulmonology*, *45*, 756–763.