Supporting cystic fibrosis disease management during adolescence: the role of family and friends

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Abstract

Background—Successful management of a complex disease, such as cystic fibrosis (CF), requires support from family and friends; however, few studies have examined social support in adolescents with CF.

Methods—Twenty-four adolescents were interviewed about the support they receive from family and friends. Interviews were transcribed, coded and analysed to determine the types, frequency and perceived supportiveness of specific behaviours.

Results—Both family and friends provided treatment-related support to adolescents with CF. Family provided more tangible support and friends provided more relational support. Adolescents also reported that the manner, timing and context of support behaviours influenced their perceptions of the behaviours' supportiveness. A subset of adolescents (17%) chose not to disclose their diagnosis to their friends.

Conclusions—The provision of support appears to be distinct from adolescent's perception of support and there may be some behaviours, such as treatment reminders, that are important to disease management but viewed as less supportive by adolescents. Facilitating increased social support holds the promise of improving disease management during adolescents, but more work is need to understand which aspects of support are related to management outcomes.

Keywords

adolescence; cystic fibrosis; disease management; social support

Introduction

Cystic fibrosis (CF) is a fatal genetic disease that affects multiple systems (i.e. respiratory, digestive, endocrine, reproductive) and primarily presents in Caucasian populations. The management of CF is complex and time-consuming, with daily treatments (e.g. aerosol medication, airway clearance, pancreatic enzyme supplements) requiring more than 1 h per day (Modi & Quittner 2006). In addition, patients must make significant alterations in their

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lifestyle, such as increasing calories, attending quarterly clinic visits and hospitalizations to treat pulmonary exacerbations. Patients and families also report significant adaptations in daily routines and social roles secondary to managing CF (Quittner *et al.* 1992; Modi & Quittner 2006), especially during adolescence when youth spend increasing amounts of time with peers and friends. Successfully managing CF during periods of social transition, such as adolescence, requires flexibility and support from family and friends (Gallant 2003; De Civita & Dobkin 2004; Kazak *et al.* 2009). Yet, little is known about the roles family and friends play as facilitators or barriers to treatment adherence and disease management during adolescence. The primary aim of this study was to describe the supportive and non-supportive behaviours provided to adolescents with CF from family and friends.

Adolescence is marked by the increasing influence of peers and friends and more time spent outside of the home, resulting in increased independence and less time with parents and families (Shroff Pendley *et al.* 2002; Modi *et al.* 2008). For youth with chronic illnesses, these changes influence how family and friends provide social support, with friends providing more treatment-related support over time (La Greca *et al.* 1995; Bearman & La Greca 2002; Gallant 2003). These changes also disrupt adherence and disease management because parents are less able to directly monitor treatment adherence (Modi *et al.* 2008) and navigate the conflicts that arise when negotiating changes in roles and responsibilities (DeLambo *et al.* 2004). Identifying and understanding what family and friends do to facilitate or impede disease management is important for guiding healthcare teams to assist patients and families through this transition while maintaining appropriate disease management.

Previous research on social support in CF, while limited, has suggested that family and friends provide qualitatively different types of support (Graetz *et al.* 2000; Foster *et al.* 2001). Graetz and colleagues (2000) conducted semi-structured interviews with 35 Australian adolescents with CF to identify behaviours provided by family and friends and perceived as supportive or non-supportive. Results suggested that adolescents reported more treatment-related support (e.g. reminders about treatment, helping with treatment-related tasks) from family than from friends, but reported more companionship support (e.g. acceptance, encouragement) from friends. Uniquely, Graetz and colleagues also asked about non-supportive or unwanted behaviours, such as nagging about treatments or being teased by peers. They found that these unwanted behaviours were uniquely related to psychological adjustment, highlighting the importance of identifying both the supportive and non-supportive behaviours provided by family and friends. Foster and colleagues (2001) also used qualitative methods and reported that friends influenced adolescents' disease management and that throughout adolescence parents continued to be involved in providing reminders, encouragement and assistance in completing treatments.

Both of these studies provide preliminary evidence that both family and friends support the management of CF during adolescence. Unfortunately, neither study documented specific supportive and non-supportive behaviours, making it difficult to identify which supportive behaviours youth found to be helpful. The current study used semi-structured interviews to collect, code and organize specific family and friend behaviours related to disease management.

Methods

Participants

Twenty-four adolescents with CF were recruited from two specialty care clinics in South Florida and Cincinnati. Mean age of participants was 15.73 ± 1.83 years, 50% were female and 17% were Hispanic. Participants' lung functioning, measured using forced expiratory

volume in 1 s (FEV$_1$ % predicted), was 73.66% ± 24.10, reflecting mild disease severity on average. Eligible participants included those aged 11–18 years who were diagnosed with CF and spoke English.

Procedure

Participants were identified by the medical teams, sent a letter informing them about the study and approached following a regularly scheduled clinic visit. Both institutional review boards approved all study procedures. Parent consent and adolescent assent were obtained prior to participation. At the beginning of the semi-structured interview, participants were asked to list the first name and relationship of the individuals comprising their social support network, including family and friends. They were also asked to indicate how close they felt to that person (i.e. not close, somewhat close, close) and whether the person was aware of the participants' CF diagnosis. Participants were then asked about the supportive and non-supportive behaviours provided by their support networks.

The semi-structured interview was divided into four sections addressing both supportive and non-supportive behaviours from family and friends. Each section began with a general question, 'What do your [family/friends] do to help you with your CF?' or 'What do your [family/friends] do that gets in the way of your treatments?' These questions were followed by more specific queries about different components of the treatment regimen (i.e. oral medications, nebulized medications, airway clearance, pancreatic enzyme supplements, diet, exercise, illnesses, clinic visits and hospitalizations), as well as behaviours intended to support adolescents during periods of emotional distress. Following identification of each supportive or non-supportive behaviour, participants were asked about the frequency and perceived supportiveness of each behaviour. Because no previous study has reported the frequency of specific supportive behaviours, the frequency questions were asked in an open format (e.g. 'How often is this support provided?') to better understand the natural reported frequency of these behaviours. Reported frequencies were then coded to indicate the number of times a behaviour occurred per week. For example, a daily behaviour was coded as 7, a weekly behaviour as 1 and a monthly behaviour as 0.25. In contrast to frequency, perceived supportiveness was rated on a 7-point scale from '*very unsupportive*' to '*very supportive*'. Interviews were audiotaped and then transcribed for coding.

Analytical approach

The transcripts were coded using template analysis (King 1999) in which specific supportive and non-supportive behaviours were first identified and then assigned to hierarchical categories based on a template developed from prior literature. This template was then modified through an iterative process to better represent the data from the transcripts. The goal was to arrive at a template that adequately described the large array of supportive and non-supportive behaviours identified by participants. The initial template was based on general categories of support identified in the literature (Bearman & La Greca 2002; DiMatteo 2004) and included four types of support: (1) *informational* (e.g. providing knowledge or information); (2) *emotional* (e.g. listening or talking about life experiences); (3) *tangible* (e.g. providing direct assistance with a task); and (4) *relational* (e.g. providing a sense of belonging to a social group). Non-supportive or unwanted behaviours were added as a fifth category because they have been notably absent from previous work on social support in chronic health conditions (Gallant 2003). Coders identified specific behaviours in the transcripts and recorded the participant's description of the behaviour, the source of support (e.g. parent, sibling, friend), the reported frequency and rating of supportiveness. These descriptions were then categorized according to the template. The categories were then reviewed by a team of clinicians and researchers familiar with CF who were not involved in other aspects of the coding process. The task assigned to this team was to judge

if the descriptions within each category were referring to the same behaviour. The template was modified when the template assigned descriptions of distinct behaviours to the same category. Descriptions were then reassigned to the new template. This process continued until the team agreed that each category described a homogeneous set of behaviours.

Results

Description of support networks

The size of family networks ranged from 4 to 10 (mean = 6.71 members), with adolescents describing relationships with about half (52%) of these individuals as 'very close'. Friendship networks ranged in size from 1 to 13 (mean = 7.75 members), with 78% of those individuals having some knowledge of the adolescent's diagnosis. The majority of adolescents (58%; $n = 14$) told everyone they listed in their network about their CF, while a smaller number reported that only a few of their friends (17%; $n = 4$) knew they had CF. Importantly, these four individuals stated that their friends were told about the diagnosis by a parent or family member without their permission, and they would have preferred that these disclosures had not occurred. The remaining participants shared their diagnosis with some, but not all, of their friends (25%; $n = 6$).

Classification of supportive and non-supportive behaviours

The interviews generated 489 behaviours from family members and 413 behaviours from friends. Twenty per cent of interviews were coded by independent research assistants to establish inter-rater reliability, yielding an intra-class correlation coefficient of 0.95. These behaviours were then classified using the initial template of four types of support (*informational, emotional, tangible, relational*) and *unwanted behaviours*. We made changes to the initial template to better describe the behaviours. First, we found that youth did not identify behaviours that were solely informational so we dropped this category from the template. Next, we observed that treatment-related behaviours tended to cut across a number of categories and often the same behaviour was described differently by different adolescents. For example, treatment reminders were described both as tangible help (e.g. 'I forget to do [treatments] and my mom has to remind me') and a sign of caring (e.g. 'I wake up knowing I am not alone because she has my back and will remind me if I forget my treatments'). Because of these different descriptions and because the focus of the study was to describe social support specific to treatment management, we decided to create a distinct category for treatment-related support. Finally, we included a number of subcategories to provide a more accurate description of the behaviours described by participants.

The final template consisted of five overarching categories (*treatment-related, unwanted, tangible, emotional* and *relational*), with 53 subcategories for families and 51 for friends. There were 19 family and 18 friend behavioural categories identified by at least five adolescents. Of these more frequently endorsed behaviours, 28 were unique to either family or friends, while nine were common to both family and friends (Tables 1 and 2).

Adolescents' perceptions of non-supportive treatment-related behaviours

While adolescents clearly identified some treatment-related behaviours, such as nagging, annoying or unwanted, they reported being reluctant to rate family members or friends as being 'unsupportive' when engaging in these behaviours. There were a number of reasons provided for this discrepancy. First, they recognized the need for persistent reminders even when they are annoyed by them. One participant reported,

> [Mom] keeps telling me to do it whether I want to or not, she knows that it's going to help me so it's pretty supportive.

While another stated,

> [Mom] usually tells me to do [airway clearance] daily 'cause sometimes I don't like doing it so she usually has to tell me or else I won't do it.

Participants also reported that parents sometimes let them 'slack off' their treatments and reported this lack of monitoring as unsupportive. They also recognized that nagging and other unwanted behaviours come from good intentions. One adolescent stated,

> Their intentions are good but the way they pursue it isn't that wonderful. I'd rather them tell me to do it instead of them yelling at me to do it. I mean I'm a person, too, I forget things.

This adolescent identified the tone or manner in which a treatment reminder is given contributes to adolescents' negative perception of what otherwise may be a supportive behaviour. Similarly, one adolescent talked about reminders from her friend,

> She pretty much says, 'Hey ok, if we're going to go out, you know, just like, let's get your meds done.' She wouldn't say, 'Ok you have to do your meds now' she'd say, 'So let's get your meds done just before we go or whatever so we don't have to do it later.' She'll present it in the way that it's not like something I have to do.

She rated her friends' reminders as very supportive because they were as encouraging and not as demanding the treatment be completed.

Adolescents also mentioned other factors that influenced their perceptions of support behaviours. They reported becoming annoyed when reminders were given after the treatment was completed or when the adolescent has a plan to complete the treatment. For example, one youth stated,

> I get annoyed 'cause sometimes [mom] reminds me and I already did them.

When talking about support from a close friend, another participant said,

> It starts to get a little nagging at times, he's like 'You gotta do it, you gotta do it.' And I'm like, 'I know, I have a set time for this. I'll do 'em, don't worry!'

They also found reminders annoying when the reminder interrupted other activities. For example, one participant stated,

> Well, like they'll tell me to do stuff. And if I'm talking on the phone or hanging out with my friends, then I don't want to do it and it gets on my nerves.

Another participant said,

> Well sometimes like when I want to watch a show or something, she tells me to do my treatment, so I have to stop the activity and I go do it – that gets annoying.

Adolescents also reported their annoyance with treatment reminders depended on their mood. One adolescent said,

> 'cause sometimes she'll say it and it'll really get to me and I'll be like, 'Don't tell me what to do' or 'I'll do whatever I want', you know, 'I can take care of myself '. So it's not that she's saying anything differently, it's just the way I'm perceiving it that day.

Another adolescent stated,

> If I'm in one of those aggressive type of 'Don't tell me what to do' kind of moods, if somebody reminds me to do something, it makes me very angry, and I'll not do it just to spite them.

Discussion

This study described a number of supportive and non-supportive behaviours provided by family and friends to adolescents with CF. The support covered many aspects of disease management including daily treatments, routine clinic visits, hospitalizations, managing health information among peers and dealing with emotional distress related to the illness. Across these aspects of care, there were differences in the amount and type of support provided by family and friends. However, both groups appeared to influence disease management during adolescence.

Adolescents reported similarities and differences in the treatment-related support they received from family and friends. Both provided treatment reminders and treatment monitoring (e.g. asking about treatments), and helped complete the treatments. Families, however, tend to provide tangible support of treatment such as preparing medication or providing rewards for completing treatment, whereas friends tend to provide more relational support such as encouragement. Beyond the type of support, the frequency of social support appeared to differ between family and friends. Adolescents indicated that family members provided treatment-related support on nearly a daily basis, while friends provided treatment-related support on a weekly or biweekly basis.

In terms of unwanted behaviours, family and friends nagged adolescents about doing their treatments. They differed, however, in other unwanted or non-supportive treatment-related behaviours. Families tended to engage in more conflict around treatment while friends tended to plan activities that conflicted with treatments. Results from adolescents' perceptions of treatment-related support suggested the manner, timing and context of the behaviour contributed to adolescents' perception of its supportiveness. It remains to be seen, however, if these same components contribute to disease management outcomes, such as treatment adherence. It is also evident that adolescents recognized the importance of treatment-related support and were appreciative of the support they received, even when they found it to be annoying. They also recognized that behaviours such as persistent treatment reminders might be most useful when there is limited desire to complete the treatment, but also mentioned that the reminders are most annoying when desire is low. Understanding the relationships among the actual provision of support, adolescents' perceptions of that support and disease management outcomes is an important area of future research that will aid clinicians in knowing what aspects of treatment-related support are most important to improving management of CF.

Outside of daily treatments, results suggested that youth received different types of support from family and friends. Similar to findings for treatment-related support, family seemed to provide more tangible support, especially during clinic visits and hospitalizations, while friends tended to provide more relational support, especially around exercise and managing social networks during periods of illness (e.g. giving friends updates about participant's condition). The unwanted behaviours also tended to be distinct between family and friends, with family members engaging in more controlling behaviours and friends in more teasing and gossiping. One commonality between unwanted behaviours from both family and friends was a focus on privacy and control of health information – adolescents did not like being asked unwanted questions about their illness or their health information being shared without their permission. This finding regarding privacy suggests adolescents' concerns about disclosure of their diagnosis to friends may be an important barrier to accessing support from their peer networks.

Peer support may not be available or accessed by all adolescents. There were differences in how adolescents informed their friends of their diagnosis. While a majority (58%) informed

their entire friend network, a smaller percentage (25%) told only a few select friends, and 17% of the adolescents had not voluntarily shared their diagnosis with their friends. It is possible that the one in six adolescents who did not voluntarily disclose their diagnosis had limited access to treatment-related support from friends. Recent work has suggested that >95% of adults with CF have disclosed their diagnosis to at least one friend (Modi *et al.* 2010), suggesting that adolescents may decide to disclose their disease as they mature. The decision to disclose can be a personal and complicated process. Disclosure in adults is related to disease severity, gender and the nature of the relationship (e.g. family, friend, colleague) (Modi *et al.* 2010), but little is known about why adolescents with CF choose not to disclose their diagnosis to friends. Understanding this process may provide insight into how best to promote better treatment adherence in adolescents (Shroff Pendley *et al.* 2002).

While this study represents a valuable step in describing social support for adolescents with CF, it had several limitations. First, similar to prior research on social support in CF, the sample size was small and only included adolescents' perspectives. The purpose of the study was to identify a broad range of supportive and non-supportive behaviours that support disease management in this population and thus did not focus on the specifics around each component of treatment (nebulized medications, pancreatic enzyme supplements, airway clearance and dietary modification). It is likely that some behaviours may be more helpful during some types of treatments than others. For example, reminders around a frequent but relatively simple task such as taking enzymes with each meal may be more effective than reminders for more burdensome tasks such as nebulized medications. Similarly, spending time with the adolescent during treatment may be more helpful during the more burdensome treatments than during the relatively simple treatments. Finally, this study did not include measures of disease management, limiting our ability to examine how social support is related to health outcomes.

The findings from this study contribute to a growing body of literature detailing specific supportive and non-supportive behaviours provided by family and friends to adolescents with CF. Identifying the most common supportive and non-supportive behaviours for adolescents with CF is important for understanding and possibly attenuating the decrease in adherence commonly reported during adolescence (DiMatteo 2004). Before such progress can be realized, it will be important to understand which family and friend behaviours are related to improved CF management. Studies linking social support to improved CF management are needed and are in progress (Barker *et al.* 2010). When examining these links, our results suggested that the frequency of support should be examined separately from adolescents' perceptions of supportiveness. For example, routine treatment reminders may be viewed as annoying or labelled as 'nagging', but they may also facilitate better adherence than infrequent reminders. Understanding which behaviours promote better disease management may assist healthcare teams in facilitating more effective support from family and friends.

Acknowledgments

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Key messages

- Support from family and friends is thought to contribute to successful disease management.

- Families and friends provide different types of support with families providing tangible support, such as treatment reminders, and friends providing relational support such as encouragement.

- Adolescents' perceptions of treatment reminders differ from the actual provision of support and are influenced by the timing and context in which the reminders were delivered.

- There is evidence that some adolescents are reluctant to disclose their diagnosis to their friends, who can be a useful source of support.

- More work is needed to understand the context surrounding provision of social support, to identify which types of support best facilitate disease management and to identify the reasons adolescents choose not to disclose their diagnosis to their friends.

Table 1

Most common support behaviours provided by family

Supportive or unsupportive behaviours	n	Ratings of supportiveness (7-point scales)[*] Label (mean)	Reported frequency (in weeks)[†] Label (mean)
Treatment-related			
• Reminded the teen about treatments.	20	Very supportive (2.62)	Twice a week (2.36/week)
○ Prepared medications and treatments.	11	Very supportive (2.73)	Every other day (3.45)
• Helped do treatments.	5	Very supportive (2.77)	Daily (5.74)
○ Provided rewards for completing treatments.	5	Very supportive (2.50)	Every 2 weeks (0.52)
• Monitored treatments and health.	5	Very supportive (2.66)	Daily (7.00)
Unwanted behaviours			
○ Was intrusive or controlling.	11	A little unsupportive (−1.04)	Once a month (0.31)
• Nagged about treatments.	8	Neutral (−0.46)	Twice a week (1.94)
○ Engaged in conflicts and arguments about health outcomes and treatment.	8	A little unsupportive (−1.41)	Every 2 months (0.12)
• Interfered with treatment by providing competing activities.	5	A little unsupportive (−1.20)	Twice a week (2.00)
Tangible support			
○ Provided comfort items when teen was ill or in the hospital.	12	Supportive (2.48)	–
○ Provided transportation to clinic.	10	Very supportive (2.57)	–
○ Helped navigate medical system.	9	Very supportive (2.56)	–
○ Accommodated teen's dietary needs.	9	Supportive (2.44)	Twice a week (1.89)
Emotional support			
○ Provided positive attention (visiting when ill, show interest in activities).	16	Very supportive (2.67)	Twice a week (2.62)
• Helped to improve mood when feeling down by talking, doing activities or telling jokes.	15	Supportive (2.47)	Every 2 months (0.10)
Relational support			
○ Allowed for appropriate autonomy in decision making and activities.	8	Very supportive (2.50)	Every 2 months (0.19)
• Accompanied teen when doing physical activities, such as outdoor activities, sports and exercise.	8	Supportive (2.44)	Every 2 weeks (0.63)
• Provided distractions from illness.	8	Supportive (2.13)	Every 2 weeks (0.56)
• Were flexible in scheduling activities to accommodate treatments.	6	Very supportive (2.50)	Once a week (1.33)

[*] Seven-point scale: −3 *very unsupportive* to 3 *very supportive*.

[†] Frequencies were not reported for behaviours that occurred exclusively in the context of illness, clinic visits or hospitalizations.

Shaded bullets indicate behaviours provided both by family members and by friends. Behaviours were ranked according to the number of adolescents who endorsed the behaviours.

Table 2

Most common support behaviours provided by friends

Supportive or unsupportive behaviours	n	Ratings of supportiveness (7-point scales)[*] Label (mean)	Reported frequency (in weeks)[†] Label (mean)
Treatment-related			
• Reminded the teen about treatments.	15	Supportive (2.08)	Every 2 weeks (0.41/week)
○ Encouraged teen to do treatments.	11	Supportive (1.98)	Every 2 weeks (0.49)
• Monitored treatments and health.	10	Supportive (1.95)	Every 2 months (0.15)
○ Inform parent or teacher when teen is ill.	7	Very supportive (2.57)	–
• Helped with treatments.	6	Very supportive (2.61)	Every 2 weeks (0.35)
Unwanted behaviours			
• Interfered with treatment by providing competing activities.	11	Unsupportive (−1.07)	Every 2 weeks (0.38)
• Nagged about treatments.	9	A little supportive (1.02)	Weekly (0.76)
○ Engaged in conversations which the teen viewed as intrusive.	8	Unsupportive (−1.56)	Every 4 months (0.07)
○ Was critical of the teen (teasing, arguing, spreading rumours).	7	Unsupportive (−1.95)	Every 2 months (0.10)
Tangible support			
○ Helped ensure there was ample food for the teen (went out to eat, shared food, purchased food).	11	Supportive (2.09)	Monthly (0.77)
○ Helped with school work when teen was ill or in the hospital.	7	Supportive (1.79)	–
Emotional support			
○ Showed concern (visiting or sending cards when ill, asking how the teen is feeling).	19	Supportive (2.14)	Every 2 weeks (0.54)
• Helped to improve mood when feeling down by talking.	18	Supportive (2.28)	Every 2 months (0.17)
Relational support			
• Accompanied teen when doing physical activities, such as outdoor activities, sports and exercise.	20	Supportive (2.35)	Every 2 days (2.61)
○ Help manage the teen's social network (informing friends of condition, making introductions).	9	Supportive (1.72)	Every 2 months (0.13)
○ Showed they accept the teen by calling or visiting.	8	Very supportive (2.56)	Every 2 weeks (0.60)
• Provided distractions from illness.	8	Very supportive (2.56)	Every 2 months (0.09)
• Were flexible in scheduling activities to accommodate treatments.	6	Very supportive (2.50)	Once a week (1.33)

[*] Seven-point scale: −3 *very unsupportive* to 3 *very supportive*.

[†] Frequencies were not reported for behaviours that occurred exclusively in the context of illness, clinic visits or hospitalizations.

Shaded bullets indicate behaviours provided both by family members and by friends. Behaviours were ranked number of adolescents who endorsed the behaviours.