Knowledge, interests and educational needs of adults diagnosed with Cystic Fibrosis after age 18

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Abstract

Background: Little is known about the knowledge, interests, or educational needs of those diagnosed with cystic fibrosis (CF) as adults or the extent to which they find available information helpful. The purpose of this inquiry was to address these gaps.

Methods: A mailed survey, completed by an international sample (N = 130) recruited through internet sites and CF Centers, collected quantitative and qualitative data to address five research questions. A response rate of 74.3% was achieved.

Results: Most participants (67.4%) said they knew little or nothing about CF at diagnosis. Of the 71.5% who indicated they received patient education, 26.9% felt they were given 'too little'. At diagnosis, most wanted disease-related information about CF. Over time they expressed interest in topics related to quality-of-life, such as CF research efforts, alternative medicine and employment issues. Three-fourths (75.4%) were active information seekers, but 60.2% were less than satisfied with what they found. Qualitative responses indicated participants did not 'see themselves' in available materials, which many described as 'depressing'.

Conclusions: Medical caregivers must be aware of and respond to the unique educational interests and needs of their adult-diagnosed patients. Additional research is recommended to better understand how patient education benefits these adults.

Keywords: Cystic Fibrosis patient education; Cystic Fibrosis knowledge; Cystic Fibrosis late diagnosis; Cystic Fibrosis adult

1. Introduction

Cystic Fibrosis (CF) is a chronic, progressive genetic disease most often diagnosed in infants and children. However, a number of cases are identified in adults. An analysis of the CF Foundation patient registry data for 2001 indicated that 9.9% (n = 100) of all new diagnoses in the US that year had been confirmed in those age 18 or older at a mean age of 34.0 years. Furthermore, the incidence of delayed diagnosis is expected to increase. In a paper presented to the WHO Genetic Epidemiology meeting in Genoa, Italy, in 2002, Gruenert, Palys, Lahiri and Widerman pointed out that the identification of over 1000 mutations and the wider availability of genetic testing now make possible the diagnosis in those who have atypical symptoms and/or achieve negative, or equivocal, sweat test results.

Research has established that, as a group, those diagnosed as adults display better lung function, higher rates of pancreatic sufficiency, fewer complications, and longer life expectancy than do adults diagnosed as children [1–3]. They are also more likely to be married, parents and employed full time [3]. In an exploratory study, Widerman found that these unique characteristics, as well as the timing associated with adult diagnosis, have important implications for patient education and support. The 36 men and women who participated indicated they wanted information they could use to help them identity as individuals with CF, maintain quality-of-life and develop hope. Yet, most available resources were targeted to parents, and contained illustrations of infants, or were presented in cartoon format for young children (who constitute the majority of new diagnoses). These also reflected the most common presentations of the disease, so that those diagnosed as adults, whose symptoms are often atypical, could not 'see themselves' in what they read. The few materials directed to an adult audience assumed familiarity and experience with CF and, therefore, did not provide basic information or discuss the impact of a CF diagnosis on established lifestyles [4].

Little is known about the actual and self-perceived knowledge of those diagnosed as adults, how to best
Table 1
Description of survey instrument

<table>
<thead>
<tr>
<th>Variable</th>
<th>Number of items&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Sample fixed-response items&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experience</td>
<td>28</td>
<td>Within a month following diagnosis, did you receive any information about CF? What was your primary source? How would you describe the amount? Have you ever received genetic counseling? Within the first 6 months how knowledgeable were you about these CF topics? How would you describe your knowledge about CF during the month following your diagnosis?</td>
</tr>
<tr>
<td>Knowledge</td>
<td>8</td>
<td>Now how interested are you in the following topics? Within the first 6 months, how would you describe your mood related to the following? Within the first 6 months, how hopeful did you feel about your future?</td>
</tr>
<tr>
<td>Interest</td>
<td>39</td>
<td>Within the first 6 months following your diagnosis, did you seek information on your own? How would you describe your compliance today compared to when you were diagnosed?</td>
</tr>
<tr>
<td>Mood</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Behavior</td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup> Additional items (n = 26) assessed demographic and illness-related descriptors.

<sup>b</sup> Response choices not illustrated.

educate them, or predictors of CF knowledge. But without access to educational materials responsive to their needs and interests, those adult-diagnosed may be less knowledgeable than others affected by the disease. This is troubling, because CF knowledge has been positively associated with adherence [5–8] and has been shown to help children, parents and adults understand and manage their disease [7–10].

The purpose of this inquiry was to address these gaps in order to inform the development of educational materials for this sub-population of CF adults and to guide caregivers in educating them. Five research questions focused the study: (1) How do those adult-diagnosed with CF describe their knowledge of CF at and after diagnosis? (2) What do they most want to know at and after diagnosis? (3) What are their existing and preferred informational sources? (4) Are demographic or CF-related characteristics associated with self-reported knowledge, interests, or information seeking? and (5) Are self-reported CF knowledge, interests, or information-seeking at diagnosis associated with self-reported adherence, hope, mood, or illness identity development among these adults?

2. Materials and methods

This was a cross-sectional, mailed survey study whose design, instrument and consent forms were approved by the Institutional Review Committee of the researcher’s university.

2.1. Recruitment

Men and women diagnosed with CF at or after age 18 were eligible to participate and were recruited through notices posted on CF-related web pages, in CF newsletters, on a consumer list-serv, and through notices sent to CF centers with adult programs. To volunteer, individuals responded to an email address contained in the notices. One hundred and seventy five questionnaires were mailed to eligible men and women. The response rate was 74.3% (N = 130) and represented: the continental US (n = 92); the UK (n = 5); Scandinavia (n = 23); continental Europe (n = 4); and other nations (n = 6).

2.2. Instrument

A survey instrument containing fixed-response questions (n = 107), open-ended questions (n = 6) and questions combining both (n = 18) was developed by the researcher. Item construction was informed by the findings of an exploratory study [4] as well as a content analysis of topics included in readily-available CF educational materials. Terms included in the survey (e.g. ‘knowledgeable,’ ‘optimistic,’ ‘compliance’) were not defined, in that participants’ subjective self-assessments were of interest. Table 1 provides an overview of the instrument.

Three points in time were assessed: diagnosis (encompassing 1 month); the 6-month period following diagnosis; and the present (the time of questionnaire completion). Although events, behaviors, feelings and/or knowledge were assessed retrospectively, there is evidence that those adult-diagnosed have no difficulty recalling their CF history [4].

The instrument, which took participants approximately 30 min to complete, was subjected to professional and patient review to enhance face and content validity.
Table 2
Age and diagnosis-related characteristics of participants

<table>
<thead>
<tr>
<th></th>
<th>Median</th>
<th>Mean</th>
<th>S.D.</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current age</td>
<td>33.0</td>
<td>39.6</td>
<td>10.8</td>
<td>21–73</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td>24.0</td>
<td>31.1</td>
<td>11.0</td>
<td>18–64</td>
</tr>
<tr>
<td>Years since diagnosis</td>
<td>6.5</td>
<td>8.9</td>
<td>8.0</td>
<td>0–37</td>
</tr>
</tbody>
</table>

N=130.

It was piloted using the first five respondents. Because no changes were indicated, these data were included in the sample.

2.3. Data analysis

Quantitative data were analyzed using SPSS version 10.0. Associations between nominal variables were assessed using χ² analyses. Associations involving ordinal and ratio variables were assessed using Pearson correlation, with the strength of r values evaluated according to guidelines presented by Munro [11]. Two-tailed paired t-tests were used to compare participant’s responses over time. Qualitative analysis involved grouping and counting responses to open-ended questions and assigning importance to them according to frequency of mention. Not all participants responded to all questions, but in most cases fewer than four cases were missing. Missing data were not included in analyses.

2.4. Participants

Over half of the 130 participants were female (56.2%; n=73). Table 2 summarizes the characteristics of participants related to their age and diagnosis. At the time of their diagnoses 55.0% (n=71) were married, 39.1% (n=50) had completed college and 62.3% (n=81) were employed full-time. Thirty percent (n=39) were parents, 32.9% of women (n=15) and 26.3% of men (n=24). Of these, 58.0% (n=22) had more than one child. Women, on average, had more children (M=2; range = 3 vs. M=1.5; range = 2). The questionnaire did not ask whether participants were natural, step, adoptive, or foster parents.

Participants rated their CF severity at diagnosis as follows: no symptoms, 7.8% (n=10); mild, 50.0% (n=64); moderate, 34.4% (n=44); and severe 7.8% (n=10). Over half (51.9%; n=67) were diagnosed due to pulmonary symptoms. Most (71.1%; n=91) did not receive their diagnoses from a CF physician, but 77.5% (n=100) began attending a CF center following diagnosis. Almost 90% indicated they were ‘somewhat’ (69.0%; n=80) or ‘highly’ (18.1%; n=21) compliant with appointment-keeping.

3. Results

3.1. Self-Assessed CF knowledge at diagnosis and over time

Most participants said they knew little (45.7%; n=59) or nothing (21.7%; n=21) about CF at diagnosis. When asked to assess their level of CF knowledge during the first 6 months, over a third indicated that they still knew little (30.0%; n=41) or nothing (3.9%; n=5). Yet, only 7.9% (n=10) said they were not interested in CF information at or following diagnosis.

To better understand what participants did know, they were asked to rate their at-diagnosis knowledge of five topics commonly included in CF educational materials, using a scale of 1 (‘not knowledgeable’) to 3 (‘very knowledgeable’). Responses are presented in Table 3. A two-tailed paired t-test revealed that participants felt significantly more knowledgeable about inheritance (M=2.4; S.D. = 0.7) than they did about how to care for themselves (M=1.8; S.D. = 0.6) (t=9.4; d.f. = 126; P=0.00).

Over 60% of male participants indicated that they first learned about the association of CF and sterility at diagnosis (43.9%; n=25) or within the 6 months following diagnosis (19.3%; n=11).

3.2. CF educational interests at diagnosis and over time

At the time they completed the survey, a mean of 8.9 years after diagnosis, only four participants (3.1%) said they felt they knew all they needed to know about CF. Most remained interested in learning about CF (95.3%; n=122), but many indicated that their interests changed over time (64.1%; n=82). To determine the nature of these changes, participants were given a list of 12 topics and asked to rank them according to level of interest at diagnosis and at the time of questionnaire completion. The intent was to determine the importance of each topic in relation to the others at two points in time. One hundred respondents ranked all 24 items. Their responses are presented in Table 4. The remaining participants either did not respond to all items, assigned
the same rank more than once, or were newly diagnosed (with no time elapsing between diagnosis and questionnaire completion). \( \chi^2 \) testing revealed no significant differences between those responding and not responding with respect to self-assessed knowledge at diagnosis, CF severity at diagnosis, country of residence, gender, educational level achieved, or desire for information. There were also no significant associations related to age-at-diagnosis or time-since-diagnosis.

Data indicate that topic ranks changed over time as did the intensity of expressed interest. The number one topic at diagnosis, What is CF?, was the topic of least interest at the time of questionnaire completion. Three topics: longevity; late diagnosis; and self-care sustained moderate to high interest, remaining in the top four over time. However, there were large standard deviations associated with the mean ranks, indicating a wide range of ratings for each time period represented.

To further explore educational interests, participants were asked to rate the following seven topics, both at diagnosis and at the time of questionnaire completion: late diagnosis; self-care; what the future holds; how to cope; genetics; what is CF; and alternative medicine. Rating topics, as opposed to ranking, allowed participants to indicate the full extent of their interest in each. All seven topics received mean ratings between ‘2’ (a little interested) and ‘3’ (interested). All means were higher at the time of questionnaire completion, suggesting that individuals’ interests increased over time. Late diagnosis, self-care and what the future holds were of greatest sustained interest. The topic with the largest increase in interest was alternative medicine, increasing from a mean of 2.00 (S.D. = 0.8) to a mean of 2.56 (S.D. = 0.9). There were large standard deviations for all seven topics, indicating considerable variance in the ratings assigned.

Males expressed only low-to-moderate interest in learning about sterility issues during the 6 months following diagnosis. Over one-third said they had no interest (34.7%; \( n = 17 \)) and an almost equal number said they had only some interest (36.7%; \( n = 18 \)).

3.3. CF information provided at and following diagnosis

3.3.1. Amount of information

Ninety-three participants (71.5%) recalled receiving information on CF at diagnosis. Of these, 26.9% (\( n = 25 \)) said they received ‘too little’, 53.8% (\( n = 50 \)) said they received an ‘adequate amount’, and 19.4% (\( n = 18 \)) said they received ‘a lot’. Receiving information at diagnosis was positively associated with self-assessed knowledge of CF at diagnosis (\( r = 0.38; P = 0.000 \)) and 6 months following (\( r = 0.22; P = 0.015 \)), although the strength of these associations was low.

3.3.2. Sources of information

Over half of those who received information at diagnosis said they were educated by their physicians (55.9%; \( n = 53 \)). Other sources included the CF nurse (\( n = 9; 9.7\% \)), other CF team members (4.2%; \( n = 4 \)), and others with CF (3.2%; \( n = 3 \)). Over one-fourth (26.9%; \( n = 25 \)) said they educated themselves. Of the males, almost one-half (49.1%; \( n = 28 \)) learned about sterility from the CF team, 24.6% (\( n = 14 \)) from reading educational materials and 21.1% (\( n = 12 \)) as a result of fertility testing. One male (1.8%) indicated he was unaware of a relationship between CF and sterility and one indicated ‘none of the above’.

To determine how participants learned about CF following at-diagnosis teaching, they were asked to identify their main educational source during the 6 months following diagnosis and at the time of question-
Participants’ stated sources of CF information over time

<table>
<thead>
<tr>
<th>Informational source</th>
<th>Point in time</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>During 6 months following diagnosis</td>
<td>At questionnaire completion*</td>
<td></td>
</tr>
<tr>
<td>CF caregivers</td>
<td>41.9%</td>
<td>54</td>
<td>38.8%</td>
</tr>
<tr>
<td>Reading materials</td>
<td>27.9%</td>
<td>36</td>
<td>13.2%</td>
</tr>
<tr>
<td>Others with CF</td>
<td>4.7%</td>
<td>6</td>
<td>3.1%</td>
</tr>
<tr>
<td>CF Foundation</td>
<td>1.6%</td>
<td>2</td>
<td>8.5%</td>
</tr>
<tr>
<td>Internet</td>
<td>11.6%</td>
<td>15</td>
<td>25.6%</td>
</tr>
<tr>
<td>Other</td>
<td>9.3%</td>
<td>12</td>
<td>9.3%</td>
</tr>
<tr>
<td>None</td>
<td>3.1%</td>
<td>4</td>
<td>1.6%</td>
</tr>
</tbody>
</table>

*129 out of 130 participants responded.

3.5. Evaluation of information provided at diagnosis

3.5.1. Materials

Just over half of those who received CF information at diagnosis rated the materials ‘somewhat helpful’ (53.8%; n = 50). However, participants’ written comments about the education or materials they received at diagnosis were not positive. They said most were written for/about children; were non-responsive to issues related to late diagnosis; and/or were ‘depressing.’ A woman diagnosed in 1981 wrote, ‘I got a booklet from the CF Foundation listing the median age of survival as 21. I was diagnosed at 24!’ A man diagnosed in 1997 lamented, ‘None (of the materials) addressed social, economic, psychological, or political issues and obstacles.’ Some participants wanted information explaining their generally good health statuses and/or their atypical symptoms. A 39-year-old woman related, ‘My problems are associated with my sinuses and nasal cavity.... Much information did not know how to correctly treat this aspect of the disease.’ Another participant recalled, ‘We were given two books, but only one little paragraph really applied to me.’

3.5.2. Caregivers

Responding to an open-ended question asking them for additional comments related to their late diagnosis experience, 13 participants commented that their medical caregivers did not have information to provide. A 31-year-old woman wrote: ‘Doctors need to have more information available. I had 15 min counsel with my diagnosis and that was it. I would call with a question. They would answer, but otherwise I have been on my own for information. It’s scary to have a bomb dropped on you and then it’s like here, deal with it...’.

Another young woman recalled, ‘My physicians gave me no information. I actually supplied them with articles and I have continued my self-education once I realized that physicians often do not keep up on the literature.’ Ten participants wrote that their medical caregivers did not consider their needs and emotions. A 51-year-old man diagnosed 2 years previously said, ‘The concern for my emotional health by the medical professionals was almost non-existent.’ A 37-year-old male simply wrote, ‘It seems like care is lacking.’
3.6. Education provided to families and romantic partners

One-half of participants (n = 65) stated that their biological families received no CF education from caregivers, and only 27.2% (n = 34) indicated their families were referred for genetic counseling. Even fewer spouses/romantic partners were reported to have received CF information (31.8%; n = 41). Yet, no participants indicated they did not want information shared.

3.7. Associations related to socio-demographic and other characteristics

Older age (r = 0.19; P = 0.031), higher educational level (r = 0.20; P = 0.027), longer time-since-diagnosis (r = 0.33; P = 0.001) and greater self-assessed illness severity (r = 0.22; P = 0.012) were found to be significantly, although weakly, associated with self-assessed knowledge. Additionally, age-at-diagnosis was positively associated with how much information participants wanted at diagnosis (r = 0.19; P = 0.033) and with information seeking (r = 0.19; P = 0.031). Participants hospitalized at the time of diagnosis recalled a greater interest in learning about the disease than those diagnosed as outpatients (r = 0.23; P = 0.010). Again, these associations were weak, with the variables of interest accounting for only 4–11% of the variance.

Self-assessed illness severity at diagnosis was not significantly associated with information seeking, reported satisfaction with educational materials, or desire for information at diagnosis.

3.8. Associations related to adherence, mood, illness identity and hope

There were no significant associations between self-reported knowledge of CF, either at diagnosis or after 6 months, and participants’ self-assessed adherence, anxiety, depression, or optimism. However, self-assessed knowledge of CF at diagnosis (r = 0.24; P = 0.008) was positively, although not strongly, associated with the development of illness identity (measured by asking participants the extent to which they thought of themselves as men or women with CF). Illness identity was negatively associated with hope (r = −0.31; P = 0.000) and optimism (r = −0.30; P = 0.001) and positively associated with depression (r = 0.35; P = 0.000) and anxiety (r = 0.35; P = 0.000), supporting some participants’ observations that what they learned about having CF was depressing. These r values, while significant, were not strong. There was no significant association between CF identity and adherence.

Hope, measured by asking participants how hopeful they felt, was not significantly associated with knowledge about CF. However, when specifically asked whether learning about CF affected their hopefulness, only 23.4% (n = 30) responded positively; 30.5% (n = 39) indicated that during the 6 months following diagnosis, the more they learned about CF, the less hopeful they felt.

Information seeking was found to be positively, although not strongly, associated with self-assessed anxiety (r = 0.29; P = 0.001) and depression (r = 0.24; P = 0.008), again reflecting participants’ observations that available CF information was often not positive.

4. Discussion

It is clear that the information and support needs of those diagnosed with CF as adults have not been adequately understood or met. In this study, most participants did not feel knowledgeable about CF following diagnosis. They did express a strong and on-going interest in learning about their disease, with their needs for and uses of information changing over time. They felt they knew the most about inheritance, symptoms and complications—biomedical topics often covered when CF diagnoses are communicated, but were less secure in their knowledge about how to care for themselves, information essential to maintaining optimal health. CF caregivers were cited as participants’ primary and preferred sources of information at diagnosis and at the time of questionnaire completion. Over time, reliance on the internet dramatically increased and reading decreased. Individuals’ reading may have outpaced available materials, making the constantly updated internet more appealing. Also, one-third of the sample were diagnosed prior to 1990 when the internet was not an at-diagnosis educational resource for many.

Similar to findings in other studies [10,12,13], participants in this study were interested in a wide range of topics, many of which are not covered in traditional CF educational offerings. Perhaps patient educators have a greater understanding of how to treat the body than they do of the effects of CF on patients’ lives, particularly those diagnosed as adults. Too, CF research focuses more on the biomedical and genetic than on the psychosocial, so less is known about how men and women experience this disease. Nonetheless, available CF information reflects professionals’ a priori assumptions about what those affected by CF need to know and the prevalent view of health education as a ‘tool to influence both thoughts about CF and its management’ [14], while those affected by CF want information to help them manage relationships, career decisions, family planning, emotional wellbeing, etc. In this study, a number of participants turned to patient list-serves for information, advice and support, suggesting that the real ‘experts’ on adjusting to an adult diagnosis of CF may be others who were adult-diagnosed with CF. Given these findings, the complex needs of those diagnosed as adults should
be addressed through a collaborative process that actively draws upon, and integrates, the expertise of both professionals and those living the experience. While research should actively seek CF treatments, and possibly a ‘cure,’ additional studies are needed to better understand how to help those diagnosed as adults enhance their quality-of-life while waiting.

The findings of this study raise important questions about the nature, purpose and goals of CF patient education for those diagnosed as adults, and perhaps for others with CF. A number of participants indicated that the more they learned about CF, the less hopeful they became and described what they read as, ‘depressing.’ This is troubling, in that the intent of patient education is not to decrease hope or negatively impact mood. Yet, realistically, CF is a progressive disease with an abbreviated life span, even for those diagnosed as adults. It is possible that the interest of participants in topics such as how to cope, research initiatives and alternative therapies reflected their seeking information to counteract more prevalent, and possibly upsetting, content on life expectancy, symptoms, complications and self-care. These findings suggest that CF patient education for adult-diagnosed men and women should include a broad range of topics from which they can draw as they come to terms with having CF.

Data analysis revealed that participants’ perceived knowledge about CF at and following diagnosis was only weakly associated with their developing CF identity and not associated with reported compliance. More troubling was the finding that CF identity, seeing oneself as an adult with CF, did not enhance participants’ mood, hope, or compliance. This counters the prevalent assumption that patient education promotes quality of life and increases self-efficacy. Without downplaying the seriousness of CF and the necessity for self-care, the challenge for CF educators is to learn more about what promotes hope, quality of life, and adherence in those adult-diagnosed, and plan materials accordingly.

This was a cross-sectional study involving a volunteer, convenience sample. Therefore, the findings cannot be generalized nor causal relationships assumed. Because participant recruitment was largely via the internet, men and women with access to computers and who were information-seekers may be over-represented in the sample. Data were obtained from self-report, and the mean time-since-diagnosis of almost 9 years may have affected participants’ recall. Yet, participants’ open-ended comments did not reflect difficulty recalling the events, emotions, or needs related to their diagnoses. In addition, the topics assessed in this study were not operationally defined. Participants may have unknowingly misrepresented their knowledge about a topic area and/or responded to topics without being fully aware of the content subsumed under them. Finally, not every participant responded to every item.

Nonetheless, this study represents an overdue first-step to understanding the educational interests and needs of adults late-diagnosed with CF and yielded data to guide the development of educational materials targeted to those late-diagnosed. Additional research is recommended to assess the actual knowledge of those adult-diagnosed and to further explore satisfaction with and outcomes related to the content, timing and sources of CF education from their perspective as well as their caregivers’. How, and what, knowledge about CF benefits those adult-diagnosed with CF should also be explored.

5. Implications for CF caregivers

Unfortunately, in this study, attending a CF clinic and/or being treated by a CF specialist were not significantly associated with reported patient education received or with perceived CF knowledge. Therefore, the following are recommended:

1. CF teams should periodically assess what their adult-diagnosed patients know and what they want to learn related to their disease. In addition to teaching about CF and its care, patient education should promote hope, answer questions, address fears, explain experiences and help patients cope. Given the number of males in this study who learned about their possible infertility at and months after their diagnoses, CF physicians should take particular care to address this issue.

2. CF teams should regularly assess whether adults newly-diagnosed with CF are satisfied with the content and amount of patient education they are receiving. Also, the needs of those diagnosed while hospitalized should not be overlooked. While respecting patients’ rights to confidentiality and autonomy, CF teams should also respond to the informational, support, and genetic counseling needs of the families and spouses of those diagnosed as adults. This can be a challenge to adult providers who are rarely accustomed to delivering diagnoses of CF or basic CF education, most of which is delivered by pediatricians to parents [15].

3. CF teams must supplement available educational materials with individualized teaching, drawing upon an understanding of how those adult-diagnosed differ from those diagnosed as children, and from each other, and the medical and psychosocial implications of these differences. Pairing those newly-diagnosed with others diagnosed as adults, via phone or email, should be considered.

4. CF caregivers should periodically assess what their late-diagnosed patients are learning/reading about CF. In this study most participants supplemented the CF education they received from their caregivers with...
written materials and information from the internet. CF teams, then, should make sure that their information-seeking adults are accessing reliable resources and understand how to evaluate and apply what they learn to their own, often unique, situations.

Acknowledgments

The author would like to acknowledge and credit Barbara Palys for her contributions to the design and implementation of this study. At the time of the study, Ms Palys was Chairperson of the International Association of CF Adults and Editor of that organization’s newsletter.

References