Original Article

Development and evaluation of a palliative care curriculum for cystic fibrosis healthcare providers☆

Rachel W. Linnemann a,b, Patricia J. O’Malley a,b, Deborah Friedman c,d, Anna M. Georgiopoulos c,d, David Buxton c,d, Lily L. Altstein e, Leonard Sicilian f,g, Allen Lapeya a,b, Gregory S. Sawicki b,h, Samuel M. Moskowitz a,b,*

a Department of Pediatrics, Massachusetts General Hospital, Boston, MA, USA
b Department of Pediatrics, Harvard Medical School, Boston, MA, USA
c Department of Psychiatry, Massachusetts General Hospital, Boston, MA, USA
d Department of Psychiatry, Harvard Medical School, Boston, MA, USA
e Department of Biostatistics, Massachusetts General Hospital, Boston, MA, USA
f Department of Medicine, Massachusetts General Hospital, Boston, MA, USA
g Department of Medicine, Harvard Medical School, Boston, MA, USA
h Department of Medicine, Boston Children’s Hospital, Boston, MA, USA

Received 6 December 2014; revised 6 March 2015; accepted 9 March 2015 Available online 25 March 2015

Abstract

Background: Primary palliative care refers to basic skills that all healthcare providers can employ to improve quality of life for patients at any stage of disease. Training in these core skills is not commonly provided to clinicians caring for cystic fibrosis (CF) patients. The objective of this study was to assess change in comfort with core skills among care team members after participation in CF-specific palliative care training focused on management of burdensome symptoms and difficult conversations.

Methods: A qualitative needs assessment was performed to inform the development of an 18-hour curriculum tailored to the chronicity and complexity of CF care. A 32-question pre- and post-course survey assessed CF provider comfort with the targeted palliative care skills in 5 domains using a 5-point Likert scale (1 = very uncomfortable, 3 = neutral, 5 = very comfortable).

Results: Among course participants (n = 16), mean overall comfort score increased by 0.9, from 3 (neutral) to 3.9 (comfortable) (p < 0.001). Mean comfort level increased significantly (range 0.8 to 1.4) in each skill domain: use of supportive care resources, pain management, non-pain symptom management, communication, and psychosocial skills.

Conclusions: CF-specific palliative care training was well received by participants and significantly improved self-assessed comfort with core skills.

© 2015 European Cystic Fibrosis Society. Published by Elsevier B.V. All rights reserved.

Keywords: Cystic fibrosis; Education; End-of-life care; Palliative care

Abbreviations: CF, cystic fibrosis; MGH, Massachusetts General Hospital.
☆ Meeting Presentation: This manuscript contains data that were presented in abstract form (workshop and poster presentations) at the 28th annual North American Cystic Fibrosis Conference (October 2014), held in Atlanta, Georgia: Linnemann RW, Buxton DC, O’Malley PJ, Friedman D, Georgiopoulos AM, Sicilian L, Sawicki GS, Moskowitz SM (2014) Development of a CF-Specific Palliative Care Curriculum and CF Provider Self-Assessed Competence with Palliative Care Skills. Pediatr Pulmonol, Supplement 37.
* Corresponding author at: Division of Pediatric Pulmonary Medicine, Massachusetts General Hospital, 275 Cambridge Street, Boston, MA 02114, USA. Tel.: +1 617 643 7232; fax: +1 617 643 7234.
E-mail address: smoskowitz@mgh.harvard.edu (S.M. Moskowitz).

http://dx.doi.org/10.1016/j.jcf.2015.03.005
1569-1993© 2015 European Cystic Fibrosis Society. Published by Elsevier B.V. All rights reserved.
1. Introduction

Cystic fibrosis (CF) is a life-limiting disease, yet therapeutic advances have led to dramatically improved survival. With this increased life expectancy [1], patients with CF must now cope with a more chronic burden of symptoms and treatments, including distressing symptoms such as pain, dyspnea, cough, fatigue, insomnia, nausea, depression, and anxiety [2–4]. Adult CF patients report experiencing a median of 10 chronic symptoms [4] and spending a mean of 108 min per day on treatment activities [5]. This burden of symptoms and treatments often has a significant detrimental effect on quality of life and adherence [6–11].

Palliative care focuses on improving quality of life for patients with serious illness by relieving suffering at all stages of disease, not just at end of life [12]. Palliative care should ideally be provided alongside therapies intended to prolong life. Previous studies have described a tension between CF therapeutic care and palliative care, the so-called either/or approach. This view conceived of palliative care as limited to end-of-life care and often resulted in late introduction of palliative services [13–18]. Historically, patients would experience an abrupt switch from life-prolonging therapies to palliative care in the last few days of life.

In practice, conversations about care preferences are often delayed until CF patients are too sick to participate themselves [19,20]. In contrast, caregivers report preferring that these discussions occur during a period of medical stability, so patient preferences are known [19]. In a national survey of adults with CF, 79% reported feeling comfortable talking to their CF clinician about advanced care planning, but only 28% said their clinicians had asked about it [21]. Clinical decline in CF can be sudden and unpredictable, creating prognostic uncertainty that may hinder advance care planning [22]. Providers may also hesitate to discuss palliative care because they are uncomfortable initiating such discussions, they perceive that the patient is using denial as a coping strategy, or they worry that the patient might lose hope [22,23].

To optimize quality of life, a new approach to palliative care in CF is needed, one that focuses on early intervention to improve assessment and management of burdensome symptoms and enhance support for advanced care planning [16]. Evidence exists to support an early intervention approach; among oncology patients in a randomized controlled trial, early palliative care consultation improved both quality of life and survival [24]. Unfortunately, the growing demand for palliative care services in oncology and other disease states is outrunning the current supply of palliative care specialists [25]. A primary palliative care model can help address this provider shortage. Primary palliative care refers to basic skills that healthcare providers can learn and employ at any stage of chronic disease, saving specialist referral for more complex cases [25]. This approach fits well into routine CF care, as it takes advantage of existing therapeutic relationships and minimizes care complexity.

To empower CF care teams to deliver primary palliative care, additional training in palliative care skills is needed and desired [22]. Most existing palliative care curricula are geared toward oncology and do not adequately address the educational needs of CF care providers. We hypothesized that training CF care providers through implementation of a CF-specific primary palliative care curriculum would increase their comfort level in evaluating and treating burdensome chronic symptoms, and integrating difficult conversations (e.g., advanced care planning) into routine care. The specific objective of this study was to assess change in comfort with palliative care skills among CF care team members who participated in training, using pre- and post-course questionnaires.

2. Methods

2.1. Development of a CF-specific palliative care curriculum

A qualitative needs assessment was performed with members of the Massachusetts General Hospital (MGH) CF care team to identify desired primary palliative care skills. Experts from the MGH pediatric and adult palliative care programs were consulted to refine the list of core skills. To obtain patient input, a focus group was conducted with the patient advisory council of the MGH adult CF clinical program. Based on these perspectives, a CF-specific palliative care curriculum consisting of twelve 90-minute sessions was developed (Table 1).

Sessions covered a broad range of palliative care topics relevant to all stages of disease. The director of the MGH CF Center (SMM) served as the course director and recruited session leaders from MGH and nearby academic hospitals to conduct the sessions. Palliative care clinicians led several of the sessions, including an introduction to palliative care, an overview of approaches to chronic pain, and communication workshops about difficult clinical conversations. Other sessions were led by an interventional pain physician (Session 3), psychiatrists (Sessions 6 and 8), a psychologist (Session 7), a social worker (Session 9), an occupational therapist (Session 9), and CF patients (Sessions 9 and 11). To prepare for each session, the course director provided the session leaders with a list of suggested subtopics; however, the specific content was at the discretion of the session leaders, who were encouraged to make the sessions interactive and to emphasize participation. The session leaders usually conferred with the course director prior to the session to assure that the content would be maximally relevant to the challenges facing CF care providers. Individuals with CF participated in some of the sessions (with adherence to appropriate infection control policies), when the professional session leader felt that a patient perspective would bring additional insight to the learning process. Session learning objectives are presented in the supplemental material (Appendix 1).

2.2. Curriculum evaluation

A single group pretest–posttest design was used to assess the effectiveness of the curriculum. A 32-question anonymous survey (Appendix 2) with unique identifiers was created for CF care team members to rate their own comfort with the targeted palliative care skills, using a 5-point Likert scale (1 = very uncomfortable, 2 = comfortable, 3 = neutral, 4 = comfortable, 5 = very comfortable). The survey covered a core group of skills relevant to all team members, regardless of discipline, and
Table 1
CF-specific palliative care curriculum sessions.

<table>
<thead>
<tr>
<th>Session topics</th>
<th>Facilitator(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Introduction to palliative care for CF providers: the role of palliative care in CF</td>
<td>Adult palliative care physician and pediatric palliative care physician</td>
</tr>
<tr>
<td>2. Chronic pain and discomfort 1: general approach</td>
<td>Pediatric palliative care nurse practitioner</td>
</tr>
<tr>
<td>3. Chronic pain and discomfort 2: pharmacological, and interventional approaches</td>
<td>Adult palliative care and interventional pain physician</td>
</tr>
<tr>
<td>4. Integrative therapies</td>
<td>Physician director of the hospital’s Institute for Mind Body Medicine</td>
</tr>
<tr>
<td>5. Giving bad news: balancing hope, reality, and prognostic uncertainty</td>
<td>Adult palliative care physician</td>
</tr>
<tr>
<td>6. Anxiety, depression, and sleep</td>
<td>CF psychiatrist and pediatric sleep physician</td>
</tr>
<tr>
<td>7. Cognitive behavioral therapy and motivational interviewing</td>
<td>Behavioral medicine/cognitive behavioral psychologist</td>
</tr>
<tr>
<td>8. Growing up with CF: a developmental perspective</td>
<td>Developmental psychiatrist, CF psychiatrist, and pediatric pulmonologist with expertise in transitions</td>
</tr>
<tr>
<td>9. Fitting CF into your life: personal identity and relationships</td>
<td>CF social worker, occupational therapist, and adult CF patient</td>
</tr>
<tr>
<td>10. Facing a lifespan limiting condition 1: difficult CF conversations</td>
<td>Pediatric palliative care physician</td>
</tr>
<tr>
<td>11. Facing a lifespan limiting condition 2: advance care planning</td>
<td>Pediatric palliative care physician</td>
</tr>
<tr>
<td>12. Facing a lifespan limiting condition 3: saying good-bye and coping with loss</td>
<td>Pediatric palliative care physician</td>
</tr>
</tbody>
</table>

Comprised five domains: use of supportive care resources, management of pain, management of non-pain symptoms (e.g. nausea, anxiety), communication, and psychosocial skills. Clinicians who prescribe medications (i.e., physicians and nurse practitioners) answered a set of additional questions within the pain management and non-pain management domains related to medical management of symptoms. The course was subsequently implemented over a 6-month period during an already established time for multidisciplinary CF provider meetings. Post-course, participants completed the same 32-question self-assessment survey. Participants also completed a quantitative and qualitative course evaluation. The Partners Human Research Committee reviewed the study protocol (2014P000140/MGH) and declared it exempt.

2.3. Statistical analyses

The primary analysis endpoint was change in self-assessed comfort level over all 32 items in the survey. Secondary endpoints were changes in each of five domains: use of supportive care resources (3 items), pain management skills (2 items), non-pain symptom management skills (3 items), communication skills (9 items) and psychosocial skills (4 items). Prescribers answered additional questions for two of the domains: medical management of pain (7 additional items) and non-pain management domains related to medical management of symptoms. The course was subsequently implemented over a 6-month period during an already established time for multidisciplinary CF provider meetings. Post-course, participants completed the same 32-question self-assessment survey. Participants also completed a quantitative and qualitative course evaluation. The Partners Human Research Committee reviewed the study protocol (2014P000140/MGH) and declared it exempt.

3. Results

All team members of the MGH CF clinical program (Table 2) were invited to attend the palliative care training sessions. Of these, sixteen members participated and completed the pre-course survey. At baseline, the mean overall self-assessment level was 3.0 (SD 0.4). Individual means ranged from 2.0 (uncomfortable) to 3.7 (between neutral and comfortable). These results indicate a need for additional CF provider training in palliative care skills.

Participants attended a median of ten course sessions (interquartile range, 9.5–11.3); four participants (25%) attended all twelve sessions. After completing the curriculum series, providers were significantly more comfortable with the targeted CF-specific palliative care skills than they had been before. The mean overall comfort level increased by 0.9 (SD 0.4), from 3.0 to 3.9 (p < 0.001, 95% CI 0.7–1.1) (Table 3). In contrast, the team members who attended only the first session had a mean change of 0.3 (individual changes of 0.7 and −0.1).

Among the 16 course participants, the changes in mean comfort levels in all 5 domains were also statistically significant.
with mean changes ranging from 0.8 to 1.4 (Table 3). The largest improvement was seen in comfort in the use of supportive care resources, such as identifying the integrative therapies that would be helpful for a patient. Among prescribers (n = 10), the mean comfort level increased significantly for medical management of pain (1.1) and of non-pain symptoms (0.9) (Table 4). As a sensitivity analysis, these tests were repeated on each endpoint for all team members (n = 18, of whom 12 were prescribers) and were still significant at the alpha = 0.05 level (p-values ranging from <0.001 to 0.004).

The course was well received by participants, who rated the quality of the sessions using a 5-point Likert scale (1 = poor, 2 = fair, 3 = good, 4 = very good, 5 = excellent). The mean session quality was 4.1 (SD 0.4). All participants in the course agreed that the palliative care course was helpful and were likely to recommend it to others. A majority of the participants strongly agreed that the course was helpful (63%) and were extremely likely to recommend it to others (56%).

4. Discussion

We perceived that CF care providers would be eager to receive additional training in primary palliative care skills. We therefore designed and implemented a CF-specific palliative care curriculum with input from CF care team members, palliative care specialists, and patients. The pre-course self-assessment of participants revealed a mean comfort score of "neutral", indicating a clear need for additional training in palliative care skills, even among the most experienced providers. We observed a significant impact on overall self-assessed comfort among CF care team members attending the course; after training, the mean participant comfort score increased from 3.0 (neutral) to 3.9 (comfortable). This increase is likely to be clinically significant, as providers who are more comfortable with their palliative care knowledge and skills are more likely to employ them. Nevertheless, how CF patients with advanced disease perceive the impact on their care, and whether they actually receive better care as a consequence of provider training, cannot yet be determined.

The study design had some additional limitations. Use of an uncontrolled single group design posed a risk of inherent bias toward improvement, in that the change in participant scores could have resulted from extrinsic factors unrelated to the curriculum. Moreover, we were unaware of any previously validated survey instruments that would have enabled us to assess course effectiveness more rigorously. The approach to scoring was thus subjective and uncontrolled, limiting our ability to draw objective, generalizable conclusions. In an effort to examine these limitations, we assessed the change in mean comfort level of two team members who attended only one session, and found that their mean change was less than that of the course participants. Another limitation was the reliance on self-assessed comfort as a measure of competence and skill. This was justified in part because self-assessed comfort has been used in other studies of palliative care training [26] in lieu of observational skill assessments or serial patient surveys that would be logistically complex and labor intensive, thus generally infeasible in practice. Logistical constraints also hindered us from surveying CF patients about care received from participating providers, which would have directly assessed the impact of training on patients. Lastly, course participants were from a single CF center, which could limit the generalizability of the results.

Our needs assessment revealed that CF healthcare providers are eager for palliative care training, particularly when it is tailored to the unique complexities of CF care. Most existing palliative care curricula are tailored to the care of oncology patients, yet individuals with CF have a unique burden of challenging symptoms and clinical sequelae, such as the impact of pain on airway clearance [8,9]. This creates the need for a CF-specific palliative care curriculum.

To improve quality of life for CF patients, the curriculum that we developed places particular emphasis on re-framing palliative care as a field focused on improving quality of life and relieving suffering at all stages of disease, not just at end of life. The curriculum also continually emphasizes the value of providing palliative care and standard guideline-based CF care concurrently.

Table 3
Comfort levels by domain among course participants.

<table>
<thead>
<tr>
<th>Domain</th>
<th>n</th>
<th>Pre-test mean (SD)</th>
<th>Post-test mean (SD)</th>
<th>Change (SD)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall self-assessed comfort level</td>
<td>16</td>
<td>3.0 (0.4)</td>
<td>3.9 (0.3)</td>
<td>0.9 (0.4)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Use of supportive care resources</td>
<td>16</td>
<td>2.7 (0.8)</td>
<td>4.1 (0.4)</td>
<td>1.4 (0.8)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Pain management skills</td>
<td>16</td>
<td>2.8 (0.6)</td>
<td>3.8 (0.4)</td>
<td>1.0 (0.5)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Non-pain symptom management skills</td>
<td>16</td>
<td>3.1 (0.6)</td>
<td>3.9 (0.3)</td>
<td>0.9 (0.4)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Communication skills</td>
<td>16</td>
<td>3.2 (0.6)</td>
<td>3.9 (0.5)</td>
<td>0.8 (0.5)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Psychosocial skills</td>
<td>16</td>
<td>3.2 (0.7)</td>
<td>4.0 (0.6)</td>
<td>0.8 (0.8)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Likert Scale: 1 = very uncomfortable; 2 = uncomfortable; 3 = neutral; 4 = comfortable; 5 = very comfortable.

Table 4
Medical management comfort levels by domain among prescribers.

<table>
<thead>
<tr>
<th>Domain</th>
<th>n</th>
<th>Pre-test mean (SD)</th>
<th>Post-test mean (SD)</th>
<th>Change (SD)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical management of pain</td>
<td>10</td>
<td>2.4 (0.4)</td>
<td>3.6 (0.4)</td>
<td>1.1 (0.2)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Medical management of non-pain symptoms</td>
<td>10</td>
<td>2.9 (0.5)</td>
<td>3.8 (0.4)</td>
<td>0.9 (0.5)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Likert scale: 1 = very uncomfortable; 2 = uncomfortable; 3 = neutral; 4 = comfortable; 5 = very comfortable.
and of integrating ongoing management of distressing symptoms and difficult conversations into routine care, an early intervention approach for which previous studies provide strong justification. For example, in the Project on Adult Care in CF, the number of chronic symptoms reported did not correlate with age or FEV1 percent predicted, a marker of lung disease severity [4]. Moreover, up to 50% of CF patients may not consult their care team about chronic symptoms such as pain [8,27].

Pain is a common and much-discussed chronic symptom for many CF patients [28]. A significant portion of the curriculum is dedicated to pain assessment and pharmacological treatment, but importantly also focuses on non-pharmacological treatments for pain, such as cognitive–behavioral therapy and integrative therapies. Moreover, pain often co-exists with other symptoms such as anxiety, depression, and insomnia [6,8,29]. In fact, the Project on Adult Care in CF revealed that the symptoms most distressing to patients are lack of energy, feeling irritable, and difficulty sleeping [4]. With this in mind, pain management was not allowed to overshadow consideration of other symptoms within the curriculum. Thus, the overall thrust of the curriculum is to encourage the early identification and treatment of a broad variety of chronic symptoms, which could enhance adherence and quality of life, major concerns in CF management [30].

Similar to other interdisciplinary palliative care training programs that have proven popular and successful among diverse groups of providers [31], the curriculum that we developed was uniformly well received across team members at our CF center, ranging from the most senior clinicians to interdisciplinary providers such as the nutritionist and chest therapist. Participants appreciated that the content was CF-specific and highly relevant to their patient population. Team members also enjoyed the interactive nature of the course; they valued discussing these challenging topics openly and hearing how others approach them. In addition, participants felt the interdisciplinary nature of the course was a great strength and found that they gained awareness and appreciation for the roles and perspectives of other disciplines. The interactive discussions that occurred during the training revealed that patients often raise concerns about symptoms or advance care planning with diverse providers, such as the inpatient physical therapist or respiratory therapist. This supports the importance of training providers from all disciplines in primary palliative care topics.

To change the expectations, behaviors, and outcomes of CF patients and their families that are associated with chronic symptom management and advanced care planning, we suspect that provider training in primary palliative care will be necessary but not sufficient. Beneficial changes are more likely to occur if CF patients with advanced disease also have access to an expanded array of allied health professionals and alternative services, such as occupational therapy, cognitive–behavioral therapy, acupuncture, and yoga, which may provide more effective relief from some chronic symptoms than strictly pharmacological interventions and other traditional medical approaches. Moreover, a structured assessment process, in which the CF provider and the patient systematically review chronic symptoms such as pain and anxiety, is likely to promote active referral to alternative services. Similarly, more formalized approaches are needed to integrate advanced care planning into routine CF care.

To ascertain the effectiveness of such an approach, we are currently conducting a pilot trial of chronic symptom assessment and alternative services referral for CF patients within our center, relying on patient-reported outcomes to measure efficacy. At the same time, we are surveying CF patients to obtain their opinions about how best to integrate advanced care planning discussions into routine care. It is hoped that combining provider training in palliative care with structured assessments and service referrals, as well as formalized pathways for early introduction of advanced care planning, will result in better management and outcomes for CF patients.

5. Conclusions

Self-assessment of CF care team members indicates a need for training in palliative care skills focused on management of burdensome symptoms and difficult conversations. CF providers are eager for this training, particularly when it is tailored to the unique complexities of CF care. The developed CF-specific palliative care course was well received by the participants and highly recommended. Moreover, participant self-assessed comfort with the targeted palliative care skills improved significantly after participating in the course.

Providers at other centers may find similar training helpful. Future efforts will be aimed at disseminating the curriculum by making the developed content available for other CF care centers to use and adapt to center-specific needs. Future studies are warranted to evaluate whether training CF providers in palliative care leads to improvement in patient outcomes.

Supplementary data to this article can be found online at http://dx.doi.org/10.1016/j.jcf.2015.03.005.

Acknowledgments

This project was supported through research grant MOSKOW13A0 and clinical fellowship grant LINNEM14A0 from the Cystic Fibrosis Foundation.

References
