


TRAIN-THE-TRAINER MANUAL FOR SITE EDUCATORS

MODULE 1 – IMPROVING LIFE WITH CF: MODEL AND IMPLEMENTATION

Presented by:

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Supported by: CF Foundation Award for Innovation in Palliative Care for Patients with CF (GEORGI19QI0)


Train-the-Trainer Course for Site Educators

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April 22, 2021

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Financial Disclosures

- Anna M. Georgiopoulos, MD has indicated the following relationships related to this presentation:
 - Consultant: Vertex Pharmaceuticals
 - Presentation includes off label use of medications
- Lara Dhingra, PhD and Russell K. Portenoy, MD have indicated no relationships related to this presentation.


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Welcome to the Course!

- *Improving Life with CF* is pleased to present this virtual Train-the-Trainer course for Site Educators.

Course Goals:

- Describe a strategy that can help Site Educators to train their care teams in palliative care interventions on-site, and
- Prepare Site Educators to engage their care teams in on-site education by using the support materials created through this project

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Today's Course

The course will include:

- Several case-based presentations by faculty
- Q & A session at the end of the program
 - Clarifying questions for individual presentations can be placed in the chat box within the meeting platform
 - Site Educators are encouraged to ask questions about the case-based teaching approach reviewed today; we plan to have opportunities to discuss clinical management in future programs
- This course will be recorded and available for on-demand viewing by Site Educators: improvinglifewithcf.org

TRAIN-THE-TRAINER MANUAL FOR SITE EDUCATORS

		
Time	Topic	Duration
11:00am-11:30am	Welcome Overview: Model and Implementation	30 minutes
11:30am-12:15pm	Pain Management	45 minutes
12:15pm-12:25pm	Break 	10 minutes
12:25pm-12:45pm	Gastrointestinal Distress Management	20 minutes
12:45pm-1:05pm	Dyspnea Management	20 minutes
1:05pm-1:25pm	Anxiety and Depression Management	20 minutes
1:25pm-1:35pm	Break 	10 minutes
1:35pm-2:30pm	Serious Illness Discussions	55 minutes
2:30pm-2:40pm	Break 	10 minutes
2:40pm-3:00pm	Q & A and Wrap-up	20 minutes

What is My Role as Site Educator?

- Site Educators will be responsible for conducting on-site training of care teams at each participating CF Center.

3 key components:

1. Develop a site-specific training plan
2. Conduct six 45–60-minute case-based learning sessions with care teams by using the slide-sets, at least once a month
3. Ask care teams to read the Best Practice Treatment Guides and watch the webinars that accompany each slide-set as part of the training program

Guiding Principles

- There is no “one way” to educate...
- Some strategies may fit your style, others may not...
- Take what is useful, build on your team’s specific strengths...
- Goal is not to change your overall approach to patient care...



Improving Life with CF Model and Implementation

Lara Dhingra, PhD

MJHS Institute for Innovation in Palliative Care

April 22, 2021

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Objectives

- Review the Definition of Palliative Care in Cystic Fibrosis (CF) Care
- Review the CF Foundation Palliative Care Guidelines
- Describe the *Improving Life with CF* Intervention and Site-Specific Implementation Plans
- Review the Site Educator Role in Implementation

Definition of Palliative Care in CF

- A clinical approach focused on enhancing quality of life by managing the illness burden experienced by patients with serious chronic illness, and their families, from the time of diagnosis forward

- Occurs alongside usual treatments and is individualized according to the patient’s and family’s unique sources of distress and illness burden, and personal values and preferences



Dellon et al., *J Cyst Fibros.*, 2018.

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CF Palliative Care Guidelines

- In 2017, the CF Foundation convened a 36-member multidisciplinary Committee on Palliative Care
- Established the first palliative care guidelines for CF

Special Report

Models of Palliative Care Delivery for Individuals with Cystic Fibrosis: Cystic Fibrosis Foundation Evidence-Informed Consensus Guidelines

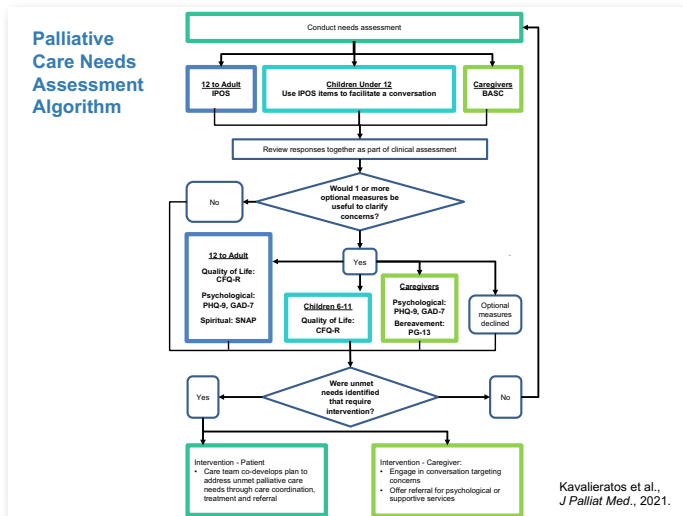
Dio Kavalieratos, PhD,¹ Anna M. Georgiopoulos, MD,² Lara Dhingra, PhD,^{3,4} Melissa J. Stabile, PhD,⁵ Elliot Rabinowitz, MD,⁶ Sarah E. Hempstead, MS,⁷ Albert Faro, MD,⁷ and Elisabeth P. Dellon, MD, MPH,⁸ The Committee on Palliative Care in Cystic Fibrosis¹

JOURNAL OF PALLIATIVE MEDICINE
Volume 24, Number 1, 2021
Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2020.0311

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CF Palliative Care Guidelines

- Recommended that CF Centers assess **individuals with CF of all ages**, along with their **caregivers**, for unmet palliative care needs, **annually, and after “triggers”** such as hospitalization or other major events
- The goal is to identify high frequency problems, such as symptom distress and the need for advance care planning (ACP)



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CF Palliative Care Guidelines

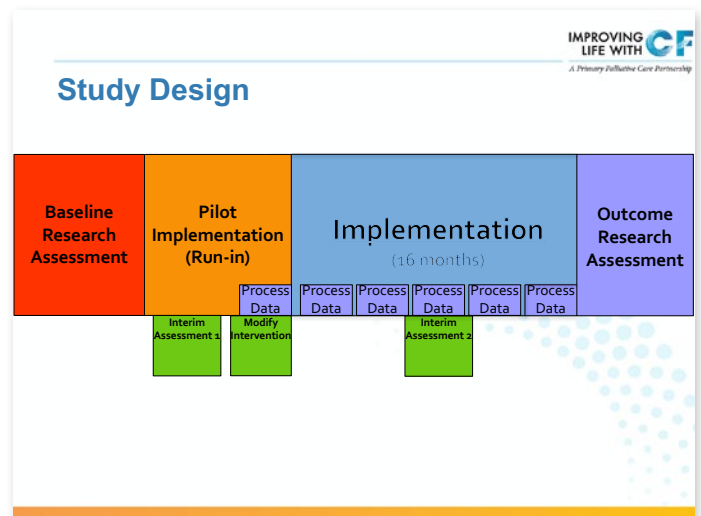
- Recommended that CF Centers provide primary palliative care concurrently with ongoing CF care across the illness course.
- CF care team members should receive discipline-specific training in primary palliative care skills.

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What is Improving Life with CF?

A new approach for primary palliative care in 5 diverse Centers that incorporates **processes** and **education/support** to help CF care teams:

- Conduct Annual and “Triggered” Screenings of Patients and Caregivers – followed by appropriate triage based on prompt assessment
- Access Best Practice Guides – for managing high-frequency problems
- Access Provider Education – supported by a Train-the Trainer approach and accredited webinars
- Conduct Quality Improvement Initiatives
- Access Patient and Caregiver Educational Materials



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Screening-and-Triage Measures

The CF Foundation recommends 2 required measures and several optional measures for patients and caregivers:

Patients (ages <12 years)	Patients (ages 12+ years)	Caregivers
Required Measures		
– Integrated Palliative Outcomes Scale (IPOS) to guide communication	– IPOS	– Brief Assessment Scale for Caregivers
Optional Measures		
– Cystic Fibrosis Questionnaire-Revised (CFQ-R) any age-appropriate subscales	– CFQ-R, any subscales – Patient Health Questionnaire-9 – Generalized Anxiety Disorder-7 item Scale – Spiritual Needs Assessment for Patients	– Patient Health Questionnaire-9 – Generalized Anxiety Disorder-7 item Scale – Prolonged Grief Questionnaire

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Integrated Palliative Care Outcome Scale IPOS


– 12-item self-report measure that evaluates unmet needs for palliative interventions:

- Symptom burden
- Spiritual wellbeing
- Practical problems
- Need for information

– Concerns are rated in the past week

– Response range from:

- “0” (Not at all) to “4” (Overwhelmingly/Always);
- “0” (No Problems) to “4” (Problems Not Addressed)



Palliative Care Outcome Scale. Available at: pos-pal.org.

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Pediatric Communication Guide for IPOS “ADAPT CF”

“Assessing for Distressing Symptoms And Palliative Care Needs through Targeted Communication” (ADAPT-CF)
Middour-Oxler et al.

– 3 age categories:

- 0-3 years; 4-6 years, and 7-11 years

– 26 items



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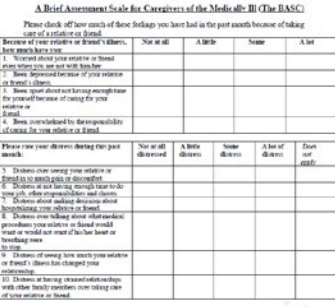
Brief Assessment Scale for Caregivers BASC

– 14-item measure of caregiver burden:

- Negative impact (wellbeing, employment, finances, health care, relationships)
- Positive impact (relative to patient, others or caregiver)

– Response range from:

- “1” (Not at all/Agree a lot) to “4” (A lot/Disagree a lot)



Glajchen et al., *J Pain Symptom Manage.*, 2005.

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Cystic Fibrosis Questionnaire-Revised CFQ-R

- Assesses 12 quality of life domains
- Multiple age categories: 0-5 years; 6-11 years; 12 and 13 years, 14 years and older
- Physical functioning subscale is predictive of disease-related mortality

Patient Health Questionnaire-9 PHQ-9

Generalized Anxiety Disorder-7 item Scale GAD-7

- Assess depression and anxiety, respectively

Modi et al., *J Pediatr Psychol.*, 2003; Sole et al., *JHLT*, 2016.

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Spiritual Needs Assessment for Patients SNAP

- Assesses desire for help with specific unmet psychosocial, spiritual/existential, and religious needs

Prolonged Grief Questionnaire PG-13

- Measure for caregivers following death of a loved one
- Has predictive validity for clinical criteria of persistent complex bereavement disorder

Sharma et al., *J Pain Symptom Manage.*, 2012; Tsai et al., *Psychooncology*, 2018.

Site-Specific Implementation Plans

- **MGH:**
 - Patients complete REDCap® survey <24 hours prior to visit
 - SW and pulmonologist review IPOS results, and then review together with the patient during virtual visit
 - Patients receive additional GI distress items
 - Follow-up interventions tracked
- **Emory:**
 - Patients receive screening packet during annual visit
 - SW reviews IPOS results with the patient before the MD/NP visit, and communicates results to MD/NP
 - SW documents outcomes

Site-Specific Implementation Plans

- **MSBI:**
 - Patients receive REDCap® survey 2 weeks prior to visit
 - SW reviews IPOS results, conducts telephonic outreach to patients for triage evaluation in 24-48 hours, communicates results to MD
 - Providers review results at weekly meeting prior to patient visit
 - SW documents outcomes
- **Northwell Health:**
 - PA sends REDCap survey® a week before scheduled visit
 - PA/MD communicates IPOS results to team for review
 - MD/other team members review IPOS results with patients during visit
 - PA documents and tracks outcomes

Site-Specific Implementation Plans

- **Stony Brook Health**
 - Patient completes REDCap® survey during annual visit
 - SW communicates positive IPOS screening results to MD, MD reviews results with the patient during visit
 - Team reviews patients who had negative IPOS screening results at weekly meeting before the annual visit
 - SW/other clinicians document and track outcomes

What is My Role as Site Educator?

3 key components:

1. Develop a site-specific training plan
2. Engage care teams in case-based education using the slide-sets
3. Encourage care teams to access the Best Practice Treatment Guides and webinars, and provide education handouts to patients

Develop a Site-Specific Training Plan

Factors to consider:

- Frequency, location, and format for case-based learning sessions? Who will participate?
 - Will pediatric and adult CF programs be trained together, or separately?
- When to ask team members to access the webinars and Best Practice Treatment Guide?
 - Prior to, or after the session? Or schedule a separate time to view the webinars together?
- How to inform teams about available resources on the project portal: improvinglifewithcf.org? E.g., patient education handouts, Discussion Board?

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What is My Role as Site Educator?

- 6 slide-sets for Site Educators to engage their care teams in case-based learning:

Module 1 – Improving Life with CF: Model and Implementation
Module 2 – Symptom Management: Pain
Module 3 – Symptom Management: Gastrointestinal Distress
Module 4 – Symptom Management: Dyspnea
Module 5 – Symptom Management: Depression and Anxiety
Module 6 – Serious Illness Discussions

improvinglifewithcf.org/train-the-trainer-manual-page

What is My Role as Site Educator?

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What is My Role as Site Educator?

- Help educate multidisciplinary team members in best practices for primary palliative care **using project resources for practice support/education:**

1. **Best Practice Treatment Guides:**
improvinglifewithcf.org/trial-support/best-practice-treatment-guides/
2. **CME/CE Webinars:**
improvinglifewithcf.org/provider-education-page/cme-ce-webinars/
3. Access the *Site Educator Training Manual* and project portal (e.g., Discussion Board) as resources, and attend *Site Educator Support Meetings* to be scheduled.
PI's can help be a sounding board/trouble-shoot challenges.

CE/CME Webinar Series: Primary Palliative Care for the CF Professional

1. Opioid Therapy for Pain Management
2. Adjuvant Analgesics for Pain Management
3. Psychosocial Pain Management
4. Assessment and Management of Heartburn, Reflux, Nausea, and Vomiting
5. Assessment and Management of Abdominal Pain, Constipation, and Diarrhea
6. Dyspnea Management
7. Psychopharmacological Approaches for Managing Anxiety and Depression
8. Psychosocial Strategies: Promoting Emotional Well-Being in Adults with CF
9. Psychosocial Strategies: Promoting Emotional Well-Being in Children and Adolescents with CF and their Families
10. Serious Illness Discussions
11. Care of the Family Caregiver: Maximizing Support While Minimizing Burden

Palliative Care Best Practice Treatment Guides for CF Care Teams

1. Pain
2. Heartburn and Reflux
3. Nausea and Vomiting
4. Constipation and Diarrhea
5. Dyspnea
6. Depression and Anxiety
7. Serious Illness Conversations

Patient Education Handouts: Palliative Care in CF

1. Pain
2. Abdominal Pain, Diarrhea, and Constipation
3. Poor Appetite, Nausea, Vomiting, and Weight Loss
4. Dyspnea and Cough
5. Fatigue
6. Stress Among Adults with CF and Their Loved Ones
7. Stress in Families of Children and Adolescents with CF
8. What is Palliative Care in CF?
9. Discussing Health Care Choices
10. Advance Directives

Acknowledgements

MJHS Institute

Stephanie DiFiglia PhD
Karen Richards PhD
Wini Schein

MGH

Nivedita Chaudhary MPH
Sophie Pollinger
Margot Hardcastle

Site Leads/Site Educators/Advisory Board Members

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Supported by: CF Foundation (GEORG19Q10)