



A Vision of Hope:

Integration of Palliative Care in Chronic Pediatric Disease^{©2011}

“Hope does not lie in a way out, but in a way through.” ~Robert Frost

Sickle Cell Disease: Facilitator’s Guide

JOHNS HOPKINS

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“The most precious gift we can offer others is our presence.” ~Thich Nhat Hanh

Dedication

This curriculum is focused on Sickle Cell Disease in honor of Miracle, Chris, Davon, and all the other young people around the world with SCD and their families. The lives of these young adults have inspired our work to improve the lives of others who live with Sickle Cell Disease.

“Although the world is full of suffering, it is also full of the overcoming of it.” –Helen Keller

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“I do not believe that sheer suffering teaches. If suffering alone taught, all the world would be wise, since everyone suffers. To suffering must be added mourning, understanding, patience, love, openness and the willingness to remain vulnerable.” ~Anne Morrow Lindbergh

Purpose of the Curriculum

The Vision of Hope Sickle Cell Disease curriculum was motivated by a commitment to integrate the principles of pediatric palliative care (PPC) into the care of individuals living with Sickle Cell Disease (SCD). Although our focus is on SCD, these materials may be applicable to other pediatric diseases that are life-threatening and life-limiting. PPC can be described as a holistic, interdisciplinary model of care that incorporates emotional, spiritual, developmental, and physical dimensions. The Vision of Hope Project builds on the curriculum developed by the Initiative for Pediatric Palliative Care (IPPC) to help facilitate the learning of practices in providing comprehensive and integrated care for adolescents and their families.

The purpose of the curriculum is to provide institutions with evidence-based curricular materials based upon the IPPC model in order to integrate in PPC concepts that will improve the quality of care for patients with SCD throughout their care continuum. The curriculum is designed to provide a training sequence of several PPC principles relevant to interdisciplinary team members. Curriculum objectives include exploring knowledge, skills, and attitudes related to patient and family care for a variety of disciplines and any level of PPC knowledge and experience.

Development of the Curriculum

The Vision of Hope curriculum was developed by a team of experts in pediatric SCD, palliative care, and medical education, with input from an external Advisory Board. It was originally piloted in a 2.5 day retreat-style and subsequent 60-90-minute in-service trainings at selected children's hospitals throughout the eastern US. Throughout this process, the curriculum has been modified based on feedback from these trainings. The development of the curriculum took place from January 2010 – January 2011 and included the following steps:

- Establishment of an Advisory Board to guide the development of the curriculum plan.
- Participants included professionals from medical institutions and advocacy groups in SCD, IPPC Curriculum development experts, and adults living with SCD.
- Definition of goals and scope for the curriculum
- Development of an instructional design for the curriculum that included general and interdisciplinary-specific breadth of components
- Development of general and specific learning objectives based on IPPC, PPC standards and the identified sequence/depth of instruction intended to achieve the learning objectives
- Assembly of the Curriculum
- Review of the draft curriculum with staff and Advisory Board
- Pilot parts of curriculum with interdisciplinary trainings at home institution
- Revise curriculum for both 2.5 day retreat and 60-90 minute in-service

Curricular Format

It is the intention of the Vision of Hope faculty and staff and Advisory Board to structure the curriculum so that it is flexible and includes a broad coverage of various interdisciplinary aspects of SCD and PPC. This approach should provide institutions the opportunity to make the most appropriate use of all of the instructional resources that are available to them. These materials can be used in training sessions for interdisciplinary health care professionals across multiple units who care for children, adolescents, and young adults with SCD.

Separate Modules

The curriculum is presented as separate modules that consist of learning objectives, sample agendas, PowerPoint presentations, film segments, discussion questions, interactive activities, resource lists, and evaluation tools. The materials can be adapted to the needs of individuals and training session participants, to your time frame, and to your training format. The materials can be used in their entirety or individual elements can be selected, modified, and used as needed. You may wish to review resource materials listed for each topic for additional background to help you prepare for delivering training sessions or designing individual sessions. In general, an interactive small group format is most effective for learning about these topics. However, these materials may also be used in a didactic, large group setting.

Three Different Formats

We propose 3 different formats for training—in-service, workshop or 2 ½-day retreat - that can be adapted to the goals and schedules of the participating institutions. For example, the in-service format is meant to align with grand rounds, noon seminars or other standard formats for training, and delivered in 60-90 minute format. Similarly, the workshop can be delivered in either a 4-hour or 8-hour formats. An institution may want to bring together members of the inpatient services with clinic and allied health professionals or they may choose to bring together clinicians from other institutions in regional format particularly for the longer workshop or 2 ½ day retreat model.

Overview of Modules

The Vision of Hope: Sickle Cell Disease curriculum is divided into eleven modules which each include learning objectives, a short, documentary film or a PowerPoint presentation, suggested handouts, and related resources for additional information. The films provided are intended to be used as “triggers” to elicit reflection and discussion during the training session. The films can be used as a stand-alone training tool by providing introductory comments and guiding discussion at the end, or you may also include PowerPoint presentations, lecture, and interactive activities depending upon your preference and time allowed. The concepts portrayed in the films are intended to elicit new thinking and responses from the audience in order to better understand patients and families and to consider personal knowledge, skills, and abilities and those of the team as a whole in response to the issues raised. The concepts are not meant to establish a standard of care or to suggest that the experiences of the patients and families in the films reflect the desired model for care.

Module 1: Introduction to Pediatric Palliative Care This section is intended as an overall introduction to the training and can be used in conjunction with any of the modules. It provides a brief overview of pediatric palliative care and how it relates to Sickle Cell Disease (SCD).
Module 2: Overview of Sickle Cell Disease Use this module to gain a broad understanding of SCD before beginning the Vision of Hope: Sickle Cell Disease curriculum.
Module 3: One Day at a Time (Film #1) This module encourages participants to think about the variations of hope that may be experienced by patients, doctors, and families living with SCD. It also focuses on quality of life and the uncertainty of living with day-to-day living with the disease.
Module 4: Respect and Patient-Centeredness “Respect and Patient-Centeredness” is a short module that focuses on integrating respect and patient-centeredness as core elements of the doctor-patient relationship.
Module 5: They Don’t Believe Me (Film #2) This module highlights the importance of utilizing effective listening and communication with patients with SCD.
Module 6: Trust (Film #3) “Trust” focuses on the trust between patients, doctors, and family members. Participants will identify various challenges to maintain trust and explore how to use palliative care to encourage building trust.
Module 7: Ethical Landscape/DMT This module surfaces the complexity of sharing the moral burden of decision making with patients and parents in the palliative care setting, and offers a tool for assisting in this process.
Module 8: Integration of Palliative Care This module explores ways to apply and integrate palliative care into the care of adolescents with Sickle Cell Disease.

Module 9: Navigating the Hard Times (Film #4)

“Navigating the Hard Times” focuses on identification of sources of pain, suffering, and resilience in patients, caregivers, and family members affected by Sickle Cell Disease.

Module 10: Transitions (Film #5)

This module discusses the difficulties presented by the complex transition between pediatric and adult care for adolescents with Sickle Cell Disease.

Module 11: Moral Angst: The Heartache of Healers (Film #6)

This module is designed to explore the internal responses (moral, emotional and spiritual) of clinicians who care for children with Sickle Cell Disease as they confront intense suffering and moral angst. Often unrecognized, these responses have a profound impact on the clinicians themselves, their interactions with patients, families and their colleagues.

Interactive Activities

The following are interactive activities included in this curriculum that can be used at your discretion, depending on time and the goals of your training.

1. Interactive Exercises
 - Quality of Life
 - Listening
 - Images of Hope
 - Ben’s Story
2. Team Meeting Exercise
3. Team Meeting Handout
4. Closing Session (for retreat or 1-day option)

Determining Your Format

The content included in this curriculum is specially designed for presentation for inter-professional learning. It is also useful for individuals who may want to learn about the content in a self-paced format. Individuals can tailor their learning experience in a sequence that best meets their needs. When the curriculum invites reflection, an individual can pause for his/her own reflection of the question or issue.

If you are using the curricula in an inter-professional format, thinking through the resources and challenges at your institution and the desired outcome of the curricular activities is vital. The inter-professional curriculum reflects relevant issues and challenges that face patients, family members, and the healthcare team. The curriculum is composed of topics that will challenge and produce increased knowledge, attitude, and skill regarding pediatric palliative care issues such as: quality of life, communication, trust, hope, and pain management. The concepts portrayed in the films are not typical curriculum subjects found in hospital institutions, but are crucial aspects of pediatric palliative care and quality patient care. In order for your training to be successful, it is important to think through what aspects of training would be of most importance and interest for your institution. You may want to consider using systematic assessment tools to understand the needs in your community and to inform your decisions about format, goals and results you hope to achieve.

Points to Remember

Conduct a Participant/Institution Needs Assessment (see below) to assist in formulating your training agenda. Being aware of the resources, challenges, and needs of your participants and institution can help you develop an appropriate agenda.

Focus on your primary goals for the training. Review each module and accompanying learning objectives, exercises, resources, and Powerpoint presentations to determine which elements best fit with your proposed outcomes.

Leave time for discussion. The films are poignant and jam-packed with potential discussion points so it is recommended that you leave a significant amount of time for group discussion. Try not to rush since the primary impact of this curriculum is the depth of emotion and empathy that can surface if time allows. Also, leave time for evaluations at the end of the session if you choose to do this.

We encourage you to review the following questions to assist you in determining the best training format for your institution:

Who

- Who is your intended audience?
 - Will it be presented to people with a broad range of experiences or focused on one profession or expertise?
 - Will it include an inter-professional team that is drawn from specialty clinics or inpatient units, or is it a hospital-wide training?
 - Do you want to include palliative care specialists?
 - Do you want to create a regional training that involves other institutions across the continuum of care?
- Whose leadership and endorsement do you need to make this a successful project?

Why

- What are you trying to accomplish? What is your central aim/purpose?
 - Raise awareness?
 - Build skills and capacity among clinicians?
 - Foster relationships?
 - **Others?**
- To what extent is there alignment with other personal, professional, or organizational values and priorities?
 - How might this training be leveraged to accomplish other important goals?
- Why would participants want to attend?
 - What would make this training relevant and useful?
 - How do you align your vision with their interests?

What

- What shifts in behavior, processes or practices are you seeking to change?
- What will people be doing differently as a result of participating in this training?
- What topics are most important to emphasize?
- What format will work best in your institution?
 - Facilitated small group discussion, large group didactic?
 - Do you want a small, intimate setting for discussion or a large room to bring in the capacity of participants?
- What will make your training effective?
 - What will be necessary to sustain the learning after the training?
- What are the complexities of what you are trying to accomplish?
 - What are some of the barriers you need to consider?
 - What resources do you have to support your efforts?

Where

- Where will this training take place (depends on number of people you want to invite, the number of people you expect, and the associated costs)?
 - During a regular training session, 1 day workshop?
 - 2 ½ day retreat?
 - In the hospital? Training center? Off site location?

- What location, date, and time is most conducive for your target audience?
- What equipment and technical assistance is needed and available?

When

- When is an appropriate time of day/month/year to plan this training?
 - In terms of institutional culture?
 - What other trainings and required compliance activities may compete with this training?

How

- How will the training best serve your intended audience?
- How should you format the training to get your best response and achieve your desired results?
- How will you know if you have been successful?

Additional Institutional Assessment Resources:

Levetown M, Dokken D, Heller, K.S., et al. for The Initiative for Pediatric Palliative Care (IPPC). A Pediatric Palliative Care Institutional Self-Assessment Tool (ISAT). Newton, MA: Education Development Center, Inc. 2002. For information, contact: M. Z. Solomon, EDC, 55 Chapel Street, Newton MA, 02458-1060. Also available at www.ippcweb.org or www.pediatricpalliativecare.org.

Sample Agendas

Sample Agendas are provided to assist in determining appropriate length and content of training options.

2.5 Day Retreat Module

Day 1

9:00 AM	Faculty and Facilitator Training
12:00 PM	Registration and Pre-Evaluation Forms
12:30 PM	Lunch Family Meeting
1:30 PM	Plenary: Welcome, Setting the Context, & Listening
2:30 PM	Small Group #1a: Opening Activity Quality of Life
3:45 PM	Break
4:00 PM	Small Group #1b: Quality of Life re: SCD/Film 1: One Day at a Time
5:30 PM	Plenary: Quality of Life as Palliative Care
6:45 PM	Dinner Team Meeting 1
	Faculty/Facilitator Meeting

Day 2

7:30 AM	Morning Reflection
7:45 AM	Breakfast
8:45 AM	Small Group Session 2: Film 2: They Don't Believe Me
10:15 AM	Break
10:30 AM	Panel: Involving Adolescents in Decision-Making
12:00 PM	Lunch Family Meeting
1:00 PM	Small Group Session 3: Film 3: Trust
2:15 PM	Break
2:30 PM	Small Group Session 4: Film 4: Navigating the Hard Times
4:00 PM	Break
4:15 PM	Small Group Session 4: Film 4: Navigating the Hard Times
5:45 PM	Team Meeting 2 Faculty-Facilitator Meeting
7:00 PM	Dinner
8:00 PM	Art Activity: Caregiver Well-Being

Day 3

7:45 AM	Morning Reflection
8:00 AM	Breakfast
9:00 AM	Plenary: Transitions
11:00 AM	Break
11:15 AM	Team Meeting 3
12:15 PM	Poster Viewing
12:30 PM	Lunch Family Meeting
1:30 PM	Small Group Session 5: Closing and Evaluation
2:45 PM	Closing Plenary
4:00 PM	Faculty-Facilitator Meeting

Sample Agendas (cont.)

1 Day/8 hour Module

8:00 AM	Faculty/Facilitator Training
9:00 AM	Registration and Pre-Evaluation Forms
9:15 AM	Plenary: Welcome, Setting the Context, & Listening
10:00 AM	Film 1
10:15 AM	Group discussion
11:00 AM	Break
11:15 AM	Film 2
11:30 AM	Group Discussion
12:15 PM	Lunch/Break/PPT Presentation?
1:00 PM	Film 3
1:15 PM	Group Discussion
2:00 PM	Break
2:15 PM	Film 4
2:30 PM	Group Discussion
3:30 PM	Closing/De-brief
4:30 PM	Closing Evaluation
4:45 PM	End

1.5 Hour Module

9:00 AM	Registration and Pre-Evaluation Forms
9:10 AM	Plenary: Welcome & Setting the Context
9:20 AM	Film 1
9:30 AM	Group discussion
9:45 AM	Closing/De-brief
9:55 AM	Closing Evaluation

Evaluation of the Training

Impact Evaluation

We do not require you to conduct an **impact** evaluation of these curriculum materials. However, if you would like to do so, please contact us. We will work with you to navigate the various methods of survey and data collection.

Process Evaluation

Although not required, we **strongly request** completion of the **process** evaluation by the facilitator or point person in charge of conducting these trainings. Providing feedback in this way will assist us in improving the Vision of Hope curriculum. The Process Evaluation can be found below and filled out on our website. Please fill out a process evaluation for each version of the training you conduct.

Process Evaluation

Please fill out a short questionnaire for each training session you implement. Your feedback will assist us in improving the Vision of Hope curriculum.

Your e-mail: _____

Which format of the training did you use?

- In-service (one time only)
- In-service (in a series)
- ½ day Workshop
- Full day Workshop
- Intensive Retreat
- Other: Please describe _____

How many hours did the training last?

Approximately how many individuals participated in this training? _____

Was the training voluntary or mandatory? _____

Please tell us about your attendees.

Which departments were represented?

- Pediatric Hematology/Oncology
- Palliative Care
- Others: Please list _____

Which disciplines/roles were represented?

- Physicians
- Nurses
- Allied health (PT, OT, respiratory therapy)
- Psychology/social work
- Clergy/chaplains
- Other: Please list _____

How would you rate your institution's training in Palliative Care? (Have you had PC training in the past?)

Which curriculum components did you use? Check all that apply.

- Intro to Pediatric Palliative Care
- One Day at a Time (Film #1)
- Overview of Sickle Cell Disease
- Respect and Patient-Centeredness

- They Don't Believe Me (Film #2)
- Trust (Film #3)
- Ethical Landscape and Decision-Making Tool
- Integration of Palliative Care
- Navigating the Hard Times (Film #4)
- Transitions (Film #5)
- Moral Angst: The Heartache of Healers (Film #6)
- Interactive Activities (Quality of Life exercise, Listening exercise, etc.)
- Team Planning Worksheets
- Reading Resources
- Closing Session
- Impact Evaluation

In your opinion, did the curriculum meet your expectations for delivering the content you anticipated?

If yes, please tell us which components worked best. If no, please tell us which components did not work well.

What recommendations would you give in order to improve the curriculum?

Did you conduct an impact evaluation of your training?

If no, why not? If yes, which evaluation strategy did you use?

Would you be willing to have us contact you for a brief summary of the results?

- Yes
- No

Learning Objectives

During this retreat, participants will:

1. Develop an understanding of pediatric palliative care principles and their relevance in the context of pediatric sickle cell disease (SCD).
2. Strengthen their understanding of the value and purpose of an interdisciplinary team approach to the integration of palliative care principles and practices in the context of SCD.
3. Explore creative strategies for enhancing the comprehensive and holistic care of adolescents and families affected by SCD.
4. Evolve strategies for encouraging reflective practice among participants.
5. Become knowledgeable about the range of educational and clinical resources currently available in palliative care and SCD.
6. Explore networking opportunities with other professionals and family members to address mutual needs and interests with regard to improving the quality of life for adolescents and families affected by SCD.

“The most beautiful people we have known are those who have known defeat, known suffering, known struggle, known loss, and have found their way out of the depths. These persons have an appreciation, a sensitivity and an understanding of life that fills them with compassion, gentleness, and a deep loving concern. Beautiful people do not just happen.” ~Elisabeth Kubler-Ross

To create an atmosphere of safety and trust in order to facilitate conversation in your training session, it is important to set-up expectations for participants to provide positive feedback and support. The following “Responsibilities for Collaborative Learning” may be provided to frame the training event.

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Responsibilities for Collaborative Learning

As a participant in the collaborative learning process at the retreat, we ask that you:

- Contribute to creating an atmosphere of trust and respect. Promote the spirit of collaborative learning among all participants.
- Listen attentively. Create a climate in which participants feel comfortable sharing personal thoughts, reflections, and feelings.
- Be clear and concise when sharing thoughts and ideas. Maintain necessary time boundaries in group discussions.
- Create space for "quiet voices" to have room for expression.
- Be respectful of the personal, professional, and cultural frame of reference of other participants.
- Act according to the guiding ethic that there is rarely only one "right" answer in any discussion. The greatest learning is likely to occur when multiple and different perspectives (medical, nursing, family, psychosocial, spiritual) are shared in respectful dialogue among participants.
- Offer personal thoughts and ideas as one option among several. Acknowledge alternate ways to view the same situation.
- Use discretion in regard to personal information that has been shared.
- Engage fully in all sessions.

“Let me keep my mind on what matters, which is my work, which is mostly standing still and learning to be astonished.” ~Mary Oliver

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General Guidelines for Facilitating Small Groups

Each small group is organized around the viewing of a film or engaging in an experiential exercise followed by group discussion. At the outset of each small group, it may be helpful for the facilitator to set a few ground rules for the discussions:

- Convey the message to participants that there is no right response, and that the group's discussion will be more valuable if there are a variety of views and perspectives.
- Remind participants that all opinions should be treated in a respectful manner, and effort should be made to include as many voices as possible. (If one or two individuals begin to dominate the discussion, make a comment about the value of hearing from as many people as possible.)
- Explain that if individuals choose to share on a personal level, their comments should not be repeated in other settings.
- Strongly encourage participants to arrive on time and stay for the duration of the seminar. Late arrivals and disruptions in the group will negatively affect the educational experience.

About the Films:

- Clarify that the film segment is not a case study to be analyzed or interpreted, but rather family stories that are provided to stimulate group reflection and discussion about clinical and organizational practice.
- The film segments include positive as well as critical comments about health care professionals. It is important to establish an atmosphere in which "mistakes" or negative behaviors on the part of practitioners are viewed as constructive learning opportunities for all participants, and not as a judgment about any single professional discipline or behavior.
- These films, while created at Johns Hopkins Hospital, are not about care at Johns Hopkins. These are films about (non-clinical) aspects of patient care (e.g., quality of life, communication, ethics) provided to young people with SCD and their families. The films are not meant to suggest a standard of care but rather to explore some of the prominent issues that arise from conversations with patients and families.
- Our hope is that the themes that arise during the training will be common across spectrums of care for adolescents with these diseases. We recognize that the stories in these films do not necessarily reflect the perspectives and experiences of all patients and families. We chose these particular patients and families to elicit certain emotional responses and to explore specific aspects of pediatric palliative care. We invite you to watch these as they are

meant to be: films to help clinicians see things from the perspective of a select group of patients and families. Notice if you find yourself wanting to debate the justification for the care these patients are receiving. If you find yourself going in this direction, pause and redirect your focus back to questions that are associated with each module.

Materials:

Facilitator's Guide

Participant handouts (all Participant handouts will be in their folder)

1 Copy of additional articles

Please review the Facilitator's Guide in its entirety.

Prepare:

In preparation for facilitating this workshop, review these materials. Give careful attention to the questions you feel are the most important messages conveyed in each film. You may not be able to get through all of the suggested questions below; use the energy of the group as a guide about the direction of content and the needs of the group.

Related References:

Familiarize yourself with the professional literature included in the Related References handout. Refer to these items when appropriate in group discussion. Each participant will receive a Related References list of additional resources which they can obtain on-line through our Vision of Hope blog (this information is contained on the resource list.) Please remind group members of the references list and encourage them to review additional resources on their own time.

Basic Outline of Small Group Sessions:

1. Introductions, checking-in, or de-briefing plenary (~5 - 10 minutes)
2. Show trigger film (~7 minutes)
3. Allow for silence and writing of structured personal reflection on film (~3 minutes)
4. Discussion (~60 - 75 minutes)
5. Application to self and home institution (~5-15 minutes)

Leading the Session: Begin the session by conveying the following introductory concepts:

In this seminar, we are going to explore.... We will watch a film segment that presents.... The videotape is approximately 7-9 minutes long. The remainder of the session will be devoted to discussion organized around focused questions.

Review the learning objectives with participants.

Play the videotape segment.

As you proceed with the discussion questions, read each one aloud and then invite discussion.

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Preparing to Lead/Planning your Training Module

Preparing to Lead:

Print:

- This Facilitator's Guide in its entirety, including the participant handouts that appear at the end.

Review:

- The "General Guidelines for Facilitating Seminars," which appear below.
- This Facilitator's Guide in its entirety, including attachments.
- The corresponding film and/or PowerPoint segment

Arrange for:

- A registration process to determine how many people will attend the seminar.
- A room large enough for the number of registered participants, set up around a table or in such a way that participants are facing each other.
- A DVD player, television monitor, flipchart, and markers. Check to determine that the equipment is working properly.

Obtain:

- A copy for each participant of the handouts and resources that appear at the end of this module
- "Seminar Learning Objectives and Discussion Questions"

Prepare:

- In preparation for facilitating this workshop, give yourself ample time to view the film, review these materials, and think about whether the material should be adapted in any way for the particular audience with whom you are working.
- Give careful attention to what you feel are the most important messages conveyed by the film and/or PowerPoint presentation.

Leading the Session:

Begin the session by conveying the following introductory concepts. Many facilitators prefer to put these ideas into their own words. Or, if you prefer, you may read the following:

In this training...

- Distribute the "Learning Objectives and Discussion Questions" handout.
- Review the learning objectives with participants.
- Play the film or PowerPoint segment.
- As you proceed with the discussion questions, read each one aloud and then invite discussion. (Questions are in bold text; notes to the facilitator are indented.)

In-Service Curriculum

**Vision of Hope: Integrating Pediatric Palliative Care into Chronic Disease
Sickle Cell Disease**

One Day at a Time

For SCD Specialists:

What one thing stood out for you as relevant/important in enhancing quality of life for patients with SCD?

For Other Clinicians:

You usually see patients with SCD when they are in crisis or not feeling well. After watching the film, did anything surprise you about the experiences of young people living with SCD?

For Everyone:

How might a palliative care approach enhance the quality of life for adolescent patients with sickle cell disease?

They Don't Believe Me

For SCD Specialists:

Is there anything in your own practical experience or education and knowledge about SCD that could explain why clinicians might not believe some patients with SCD when they talk about their experiences or their pain?

For Other Clinicians:

Did you see anything in this film that surprised you about the experiences that patients with SCD have when seeking health care for their pain, and/or about the attitudes/role of clinicians in pain management?

For Everyone:

What would need to happen for clinicians to respond differently to the suffering experienced by adolescents living with sickle cell disease?

Trust

For Everyone:

Based on what you saw in this film and your own experience, what specific behaviors build or break trust between SCD patients, families and clinicians?

How might a palliative care approach help to build trust in patient and clinician relationships?

Navigating the Hard Times

For Everyone:

Based on this film, what are the sources of patient and family suffering that might be overlooked?

Besides prescribing medicine, what are the ways clinicians can address suffering and support the inner resilience of patients with SCD?

General Discussion

Regarding what we have discussed during today's session, what change would you like to see/make in your own practice?

Are there unmet needs in the care of adolescent patients with sickle cell disease that a palliative care approach could help to address?

2.5 Day Retreat Curriculum

Module 1

Introduction to Pediatric Palliative Care

Description

This section is intended as an introduction to the training and can be used in conjunction with any of the modules. It provides a brief overview of pediatric palliative care and how it relates to Sickle Cell Disease.

Time Estimate

35 minutes

Structure

10 minutes Introduction

23 minutes Show Video: Palliative Care from the Leading Edge of the Wedge

10 minutes Group Discussion

Learning Objectives

- Understand the basics of palliative care
- Begin to explore the various roles of palliative care in the care of someone with SCD

Show Video: Palliative Care from the Leading Edge of the Wedge (22 minutes)

Group Discussion (10 minutes)

- Did you hear anything new related to the definition of palliative care?
- What are key PC components that can help in “quality of life” for an adolescent with SCD, their parents, family members, and professional caregivers?
- What is the role of hope in palliative care?

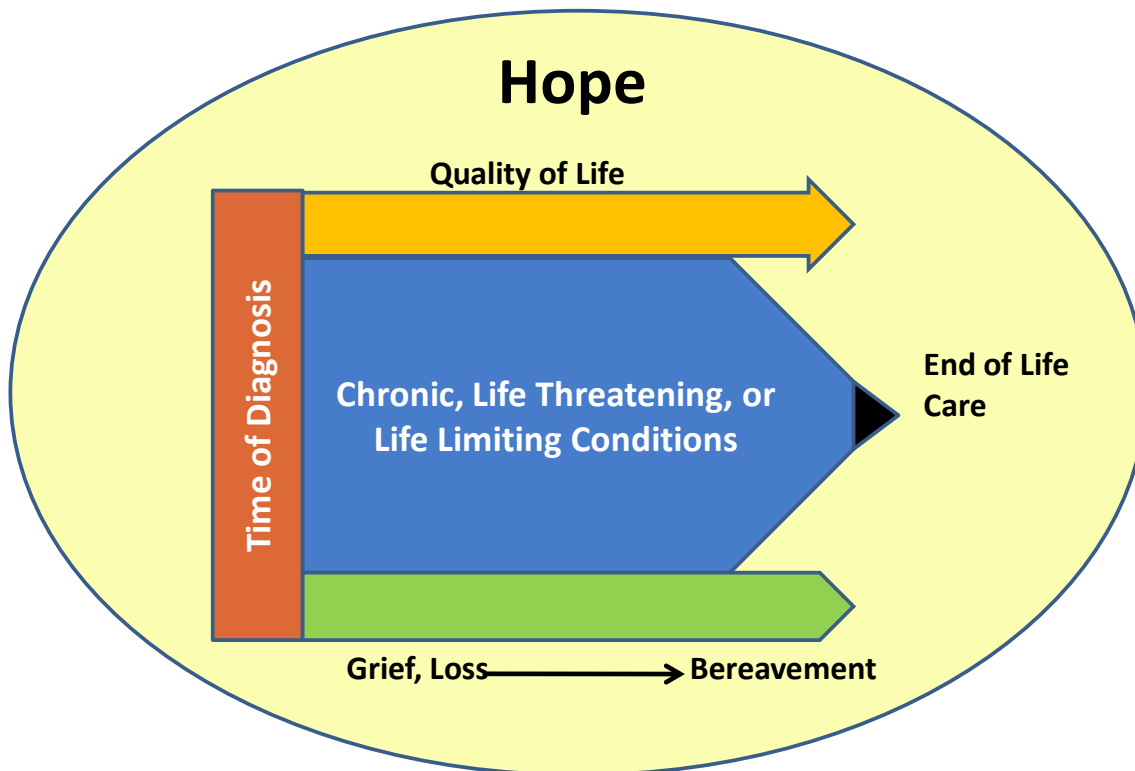
Palliative Care

“The art and science of patient and family-centered care aimed at attending to suffering, promoting healing and improving quality of life.” ~ Javier Kane, MD

Components of Palliative Care

- Quality of life
- Pain and Symptom Management
- Communication
- Ethical Decision making
- Advance Care Planning
- Grief & Bereavement

A Model of Palliative Care in Chronic Life-Threatening Conditions



Module 2

Overview of Sickle Cell Disease

Description

Use this module to gain a broad understanding of SCD before beginning the Vision of Hope: Sickle Cell Disease curriculum.

Time Estimate

30 minutes

Structure

10 minutes	Introduction
10 minutes	Show Video: Overview of Sickle Cell Disease
10 minutes	Debrief and Questions

Learning Objectives

- Explore the causes, symptoms, progression, treatment, and care for individuals with SCD.

Show Video: Overview of Sickle Cell Disease (10 minutes)

Module 3

One Day at a Time

Description

This module encourages participants to think about the variations of hope that may be experienced by patients, doctors, and families living with Sickle Cell Disease. It also focuses on quality of life and the uncertainty of living with day-to-day living with the disease.

Time Estimate

3 hours (broken up by 2 small groups and a break)

Structure of Small Group 1 (75 minutes)

12 minutes	Introduction
25 minutes	Group Introductions
3 minutes	Individual Reflection
35 minutes	Group Discussion

Themes

- Reflections on Palliative Care and Quality of Life
- Pain and Suffering

Learning Objectives (*Refer participants to Learning Objectives for this Small Group that can be found in their Participant Notebook*)

- Recognize the range of individual perspectives on what constitutes “quality of life” for patients with SCD
- Explore the role of palliative care in enhancing quality of life for patients and family members

Group Introductions (2 minutes per participant, 25 minutes total)

Ask each person to introduce themselves in the following way: Please state your name, discipline or role (physician, nurse, family member, etc.), and home institution. Then, please respond to the introductory question below. Ask each person to "distill" their comments into 2 minutes (you will need to monitor the time).

“Please respond to the following question, keeping your responses to approximately 2 minutes: The most important thing I have learned from caring for people with potentially life threatening conditions like Sickle Cell Disease is....”

Individual Reflection (3 minutes)

Ask each participant to take 3 minutes to individually reflect on the following questions (these questions will be in their participant guide).

- If you were defining “quality of life” for yourself and/or your family, what 5-6 components would be most important?
- What values underlie your definition of quality of life?
- When you were an adolescent, what meant the most to you regarding your quality of life?
- Now, think of being a patient with SCD. Would you have been able to experience these things?
- What would they have needed to be able to achieve their desired quality of life?

Group Discussion (35 min)

The remainder of this session will be devoted to exploring basic values regarding quality of life. List some of their components of Quality of life in response to the following question:

(Facilitator Note: *A flipchart could be used to capture responses.*)

- What is the “essence” of the quality of life?

(Facilitator Note: *Possible prompts regarding the essence of quality of life:*

- *What do you notice about the similarities or differences in your responses about quality of life?*
- *How do they compare to what you’ve heard from patients and their family members?*
- *What key components/values seem to be critical in defining “quality of life” for a child or adolescent with SCD?*
- What is the role of hope in quality of life?
- How can you, as a clinician, help adolescent patients increase their quality of life?
- How can patients, families, and clinicians have productive and comfortable conversations about definitions of quality of life and the implications for treatment?
- How might discussion of palliative care contribute to those conversations?

Agenda items: Refer participants to their agenda, noting there is a 15 minute break before the following small group session.

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Break (15 minutes)

Structure of Small Group 2 (90 minutes)

7 minutes	Show Film 1: One Day at a Time
3 minutes	Individual Reflection
50 minutes	Group Discussion
5 minutes	Application to Self and Home Institution
25 minutes	Group Activity

Show Film 1: One Day at a Time (~7 min)

(Facilitator Note: Inform group that Davon was one day post-inpatient stay/crisis. He is fatigued in these films.)

Individual Reflection (3 min)

Give 3 minutes for individual reflection on the film. Ask participants to write responses to the following questions:

- What are your initial responses to this film? Notice your feeling tone, body responses, and thoughts.
- What, if anything, surprised you?

Group Discussion (50 minutes)

- In our work, we see patients with SCD when they are in crisis or not feeling well. After watching the Film, did anything surprise you about the experiences of young people living with SCD?
- After seeing other parts/aspects of their life, what does that bring up for you?
- Reflect on the last session focusing on Quality of Life. What new insights, if any, do you have about what quality of life means for the patients in the film?

Unpredictability

(Facilitator Note: Introduce the next section of the discussion as “Unpredictability” and refer to how this is portrayed in the film by participants who say: “I never really know that I’ll be fine” and “I don’t know what will happen day to day.”)

- How does this unpredictability affect patients, families and clinicians?
- What do you think it is like for patients who simultaneously live their lives day by day AND plan for future?
- What impact does unpredictability have on those who don’t plan for the future?

(Facilitator note: Those who do not plan for the future may not do so due to attitudes/fears about their disease. Explore what those fears or attitudes might be.)

Hope

- What is the role of hope in managing the unpredictability of SCD?
- What do you think the patients in the film, their families and clinicians are hoping for?

(Facilitator Note: Probe possible responses such as: cure for the disease, cure for certain symptoms, cure for issues related to quality of life or emotional/physical pain, etc.)

- How do these hopes compare with your own hopes for your patients?

(Facilitator Note: After exploring participant responses, share the following: Keene and Serwint's study comparing hope between clinicians and families suggests that parents do not see a tension between hope and accepting the reality of the illness/prognosis. For them, both concepts (hope and reality) can co-exist. In contrast, clinicians view hope as being in tension with accepting the reality of the illness or prognosis. The poorer the clinicians' view of the patient's future the greater the tension with hope and the more they want parents to acknowledge the reality of the situation.)

- How do we navigate when we have different visions of hope?
- What do you think your role is in the offering of hope to patients and families? (Prompts: hope for better quality of life, alleviation of pain, cure, college, future, etc. What are some ways that clinicians can foster hope? What are some ways that clinicians may extinguish hope?)

(Facilitator Note: In Keene and Serwint's study, clinicians are mixed in their view about their role in fostering or extinguishing hope.)

Application to Self and Home Institution (5 min)

- Regarding what we have discussed during this group, what change would you like to see/make at your home institution?
- How could you add to your practice ways to encourage hope?

Group Activity (25 min)

Prep: Arrange chairs in a circle or around a table. Invite members to sit in the chairs in the circle or around a table. Place one page of flipchart paper on the wall near the circle. Have tape and post-it notes nearby.

Group Discussion Question:

Currently, there is no “cure” for SCD-although BMT may be a promising treatment. What is QOL when cure is not possible?

Individual Reflection (2-3 minutes): Think of a time when you did or said something (besides a medication) that made a difference in the QOL of a patient with SCD. Write about this experience in silence.

Group Debrief: After the period of writing, ask participants to share a sentence that summarizes what they did or said.

(Facilitator Note: Based on participant feedback, acknowledge that all of the responses represent aspects of healing, using the following quote:

*“Healing means more than a physical cure. The state of illness inflicts psychological, social, and even spiritual challenges to the ill individual. To heal is to become whole again and to return as far as possible to what one considers a normal life. Ideally, healing involves a cure, but when a cure is not possible, it still involves restoring function, maintaining function or, at the very least, regaining the sense of balance and the integration of meaning and living.” (from *The Health Care Professional As Friend and Healer: Building on the Work of Edmund D. Pellegrino*. Eds., Thomasma and Kissell, Georgetown University Press, 2000).)*

Place the pre-selected images on the table or floor in the center of the circle.

- 1) Pass out Post-it notes to each participant. Place images in center of circle.
- 2) Invite group members to view the images and choose one that represents healing to them. Each person goes in turn until everyone has an image.
- 3) In silence, ask participants to reflect on this question:
“What quality about YOU as a healer do you need to remember in the care of patients with SCD?”
- 4) Ask them to write one word that represents healing to them on their post-it note (can be related to the image, their answer to the question about their quality as a healer, or another word).
- 5) Ask participants to share the word with the group.
- 6) Ask each participant to tape their image and their post-it note word onto a flip-chart, creating a group collage. The post-it note can be placed on the collage – either on their photo or somewhere of their choosing.

- 7) When everyone has placed their image and post-it note on the group collage, invite everyone to stand together in front of the collage to reflect on the image and what it evokes for them.
- 8) End the session with a moment of gratitude to everyone for their participation in the activity.

Agenda items: Refer participants to their agenda, noting the next event is a Plenary on Palliative Care and how it relates to Sickle Cell Disease.

(Facilitator Note: *The following plenary will cover the following themes:*

- *Introduction to Palliative Care and SCD*
- *Identification of how palliative care can address physical and emotional pain experienced by patients and their family members)*

Module 4

Respect and Patient-Centeredness

Description

“Respect and Patient-Centeredness” is a short module that focuses on integrating respect and patient-centeredness as core elements of the doctor-patient relationship.

Time Estimate

20-25 minutes

Structure

5 minutes Introduction

16 minutes Show Video: Respect and Patient-Centeredness

5 minutes Debrief

Learning Objectives

- Define and review the importance of respect and patient-centeredness as concepts in the health care setting
- Describe insufficiencies in respect & patient-centeredness in sickle cell disease care
- Discuss strategies to improve the patient-centeredness of sickle cell patient/provider relationships

Show Video: Respect and Patient-Centeredness

Debrief

Module 5

They Don't Believe Me

Description

This module highlights the importance of utilizing effective listening and communication with patients with Sickle Cell Disease.

Time Estimate

90 minutes

Structure

10 minutes	Opening, Introduction of the Day, and Debriefing
7 minutes	Show Film 2: They Don't Believe Me
3 minutes	Individual Reflections on Film
65 minutes	Group Discussion
5 minutes	Application to Self and Home Institution

Themes

- Common myths about pain management/ addiction/ drug-seeking behaviors
- Sub-group Discrimination

Learning Objectives (*Refer participants to Learning Objectives for this Small Group that can be found in their Participant Notebook*)

- Understand the experiences of people living with SCD related to pain and suffering.
- Identify barriers to adequate pain assessment/treatment
- Appreciate how issues of race, class, and ethnicity can shape perceptions and assumptions about patients in regard to their experience and treatment of pain.
- Identify strategies for addressing barriers to addressing pain and suffering for people living with SCD.

Opening, Introduction of the day, and De-briefing (10 min)

- What new insights did you gain from the Plenary on Palliative Care?
- What lingering questions do you have now?

Show Film #2: They Don't Believe Me (~7 min)

Individual Reflections (3 minutes)

Give 3 minutes for individual reflection on the film. Ask participants to write responses to the following questions:

- What are your initial responses to this film? What surprised you?
- What are your thoughts about what it means for patients to feel that their experience of pain is not believed?

Group Discussion (65 min)

- What did you learn from this film about how patients are thinking and feeling about their illness, prognosis, and relationship to the health care system? (Prompts:
 - *Loss of confidence in ability to control disease*
 - *Frustration at not being heard and respected*
 - *Anger if suspects that the staff believes an addict*
 - *Distrust in the medical system*
 - *Isolation - Enhanced because patients feel like they aren't believed (suffering in silence)*
- Why are some patients' experiences of pain not believed? (Prompts: *Pain is invisible, especially as people get older, may have developed tolerance so need higher doses/patients know their doses so raises suspicion*)
- In the film, did you notice a difference in treatment between children and adults?
 - Was it surprising to you that Davon, a child, had experienced this treatment?
- Why are clinicians concerned about drug addiction in this situation? To what extent are these concerns warranted?

(Facilitator Note: *Addiction rates among patients with SCD have been reported to be within a range of 0 to 11% (Jacob) and 0 to 9% (Solomon). Encourage participants to see related references for these articles.*)

- How do you respond to Sophie's comment about "it's not the role of ED clinicians to worry about addiction"? (Prompts: *What IS the role of the ED clinician in assessing and treating patients with whom they suspect substance abuse? What is the role of other clinicians in the interdisciplinary team in addressing these concerns? What is the impact of clinician concerns about substance abuse on the care of patients with SCD?*)
- How do you respond to the suffering experienced by patients with SCD? (Prompts: *Helplessness, guilt, compassion, blaming patient, withdrawal, distance ("not like me"), burnout*)

(Facilitator Note: *Pause for a moment here to invite participants to reflect on what they wish they could do to help their patients. Invite responses from the group:*

- *How do you feel when you are unable to relieve their pain or suffering?*
- *How do you typically respond to patients who have continued pain crises?*

- What assumptions do you make?
- What behaviors or character traits do you associate with “drug seekers or drug addicts”?)
- What do we say to each other but not to the patient? (Prompts: Non-compliance, things said outside the patient room, gossip, characterization, labeling.)
- What labels do we give to patients who may not respond to advice or treatment in the way we prefer?
 - What is the impact of these labels on how we provide care?
 - How do these labels affect our relationship with patients or attitudes toward patients?
 - How do these things affect trust?
- How do patients accommodate in their behavior to get what they need? (Prompts: Importance of positive self-presentation (e.g. dress professionally): classism; changing their behavior or inflating pain scores in order to get what they need (pseudoaddiction))

When you reflect on your own doubts about validity of pain and attitudes towards patients:

- How do clinicians contribute positively/negatively to the lived experience of patients?
- In what ways do clinicians “suffer” as they provide care to these patients?

Application to Self and Home Institution (5 min)

- What role can palliative care play in addressing some of these issues:
 - Physical pain?
 - Psychological pain?
- Regarding what we have discussed during this group, what change would you like to see/make at your home institution?

Agenda items: Refer participants to their agenda, noting the next event is a Plenary on the Ethical Landscape related to Sickle Cell Disease.

(Facilitator Note: The following plenary will cover the following themes:

- What is respect? What is the relationship between respect, trustworthiness, and trust?
- What does it mean to show respect for patients as persons?
- How are discrimination and bias departures from respect?
- What are the consequences of respect for patients... or its lack?
- What are some ways in which SCD patients are not treated with respect?)

Module 6

Trust

Description

“Trust” focuses on the trust between patients, doctors, and family members. Participants will identify various challenges to maintain trust and explore how to use palliative care to encourage building trust.

Structure (~2 hours)

10 minutes	De-brief Plenary
18 minutes	Show Video: Trust
7 minutes	Show Film 3: Trust
3 minutes	Individual Reflection
65 minutes	Group Discussion
5 minutes	Application to Self and Home Institution

Themes

- Trust and Respect
- Communication
- Decision-Making

Learning Objectives (*Refer participants to Learning Objectives for this Small Group that can be found in their Participant Notebook*)

- Define trust and identify the behavioral components that can impact trust with patients, family members, and clinicians.
- Examine behaviors that build and break trust.
- Explore how the principles of palliative care can build trust in patient and clinician relationships.

De-brief Plenary: Ethical Landscape (10 min)

- What new insights did you gain from the Plenary on the Ethical Landscape?
- What lingering questions do you have?

Show Video: Trust (18 min)

Show Film #3: Trust (~7 min)

Individual Reflection (3 min)

- What are your initial responses to this film? What surprised you?
- What does trust mean to you? Write your definition of trust.
- What did you notice about your thoughts, feelings, body sensations? What do these tell you about yourself?

Group Discussion (65 minutes)

The film presented various views of trust regarding the patient, parent/family, and professionals.

- What does trust mean to patients and families in the film?
- **Patient/Family member question:** What does trust mean to you/your child with SCD?
- What are the various things that patients trust us to do?

(Facilitator Note: This question’s purpose is to elicit behaviors which comprise the various dimensions of trust that were discussed in the previous plenary, which could include:

- *keeping promises*
- *believing each other*
- *managing expectations*
- *honoring/respecting each other’s views*
- *telling the truth*)

- What things do you as clinicians trust patients to do?
- Whose responsibility is it to build trust? Patient or clinician?

(Facilitator Note: Lead Group in discussion to fill in the following matrix (write on flip-chart))

	Build Trust	Break Trust
Patient Behaviors		
Clinician Behaviors		

Patients, family, and professionals may discuss their frustration with the system, but the system mostly consists of “us.” For this discussion, we want to focus on the behaviors of both patients/families and clinicians that build and break trust.

- What clinician behaviors build trust between patients and clinicians? Refer back to the plenary session. Focus on the behaviors.

Clinician behaviors that build trust might include:

- Following through with treatment plans
- Answering questions honestly
- Inquiring about preferences
- Admitting what is not known
- Setting realistic expectations
- Empowering patients to advocate for themselves
- Respectful communication
- Listening
 - What patient/family behaviors build trust between patients and clinicians?

Patient/family behaviors that build trust might include:

- Honest appraisal of their symptoms and responses to treatment
- Following through with treatment plans
- Speaking respectfully
- Recognizing own limitations
- What behaviors break trust between patients and clinicians?

Behaviors that may break trust by patients: An example could include situations in the hospital where each doctor, nurse, or clinician that sees each patient asks them the same questions repeatedly.

- How might that be interpreted by patients? Why might this example be particularly important in this population?

Behaviors that may break trust by clinicians: Examples might include not returning calls, dismissing concerns, disrespectful interactions, impatience, not listening, unclear treatment plans, paternalistic attitude.

- What are some action-oriented responses/practices to build trust between clinicians and patients (and institution) rather than just get angry at the system?

(Facilitator Note: *As an example of how to apply the discussion on building and breaking trust, we are going to explore the concept of expectations, anger, and assumptions as examples of ways to build or break trust in the patient/clinician relationship. Frame the next section of the discussion in this way and keep the idea of building or breaking concepts in mind as you discuss the following.*)

Expectations

In the film, patients discussed their desire to be listened to and acknowledged there is no cure and they don't expect doctors to "fix" them.

- In light of this acknowledgment, what would successful treatment look like?
- What is realistic treatment to expect?
 - There can be a sense of failure on both doctor's part and patients' part when pain isn't prevented.
 - What would cause that sense of failure for the clinicians?
- What emotions might a patient experience towards their invested clinician if they are non-responsive to treatment?
 - What would cause that sense of failure for patients?
- What role can palliative care play in listening to patient, parent, caregivers?

Anger

- What role does anger play in patient/clinician relationships?
- What are the possible responses to being treated badly for patients, family members, and clinicians? (*Prompts: Potential responses include:*
 - *We take it out on each other*
 - *Take anger personally*
 - *Forget about the power imbalance between staff members and between patients and staff*)
- How does unexamined anger impact the trustworthiness of communication?

Assumptions

- What assumptions might we make about patients who come from diverse backgrounds?
 - Do you think anyone in the video is at any greater risk of being stigmatized?
 - If so, why?
 - What are the consequences of failing to honor or respect the diversity and cultural context of our patients?
- In several studies, patients and clinicians have brought up the possibility of racial discrimination. To what extent does racial discrimination impact the quality of care provided to patients with SCD?
 - What impact do these assumptions have on our communication and relationships with patients and families?
- What assumptions do you think patients/families make about clinicians?
 - What are the consequences of these assumptions on the relationships patients/families have with clinicians?

(Facilitator Note: *If there is time, discuss the following topic of adolescent decision-making. If there is not enough time, skip to Application to Self and Home Institution.*)

Adolescent Decision-Making

In the film, Davon states he knows himself and his body. His Grandmother says, "You have a voice," when referring to his treatment.

- How do you honor what patients and parents know about their child and their family while making medical decisions?
- What concerns do you think need to be heard from each individual? Clinicians, patient, parent?

Use the following matrix to explore the concerns.

- When thinking about the role of adolescents in treatment decision making, what are the concerns that need to be considered? (*Prompts: Child, family, situational factors; Goals of including adolescents; Informed Consent issues; Developmental and cognitive levels of adolescents*)

Concerns in Adolescent Decision-Making

	<i>Patient</i>	<i>Family</i>	<i>Clinician</i>
Values – which decisions, right to refuse treatment, preferences			
Capacities -cognitive, understanding of illness, expectations			
Spirituality/Culture			
Other			

Application to Self and Home Institution (5 min)

- Regarding what we have discussed during this group, what change would you like to see/make at your home institution?

(Facilitator Note: *The following plenary will cover the following themes:*

- *Introduction to the Decision-Making Tool (DMT)*
- *Exploration of a case example using the DMT)*

Module 7

Ethical Landscape/DMT

Description

This module surfaces the complexity of sharing the moral burden of decision making with patients and parents in the palliative care setting, and offers a tool that can assist in this process.

Time Estimate

~45 minutes – 1 hour

Structure

5 minutes	Introduction
16-30 minutes	Ethical Landscape Presentation
10 minutes	Debrief
5 minutes	Application to Self and Home Institution

Themes

- Pain and Suffering
- Decision-making
- Communication

Learning Objectives

- Become familiar with the decision-making tool and identify potential areas for application.
- Learn how to more effectively navigate making decisions involving morally-sensitive issues

Show Video: The Decision-Making Communication Tool (16 minutes)

De-brief Plenary: Ethical Framework for Decision Making (10 minutes)

- What new insights did you gain about ethical decision-making?
- How might you apply the decision making tool to your clinical practice?
- What new insights did you gain regarding responding to ethical conflicts?
- What lingering questions do you have?

Application to Self and Home Institution

- Regarding what we have discussed during this group, what change would you like to see/make at your home institution?

Module 8

Integration of Palliative Care

Description

This module explores ways to apply and integrate palliative care into the care of adolescents with Sickle Cell Disease.

Time Estimate

20-25 minutes

Structure

5 minutes	Introduction
12 minutes	Show Video: Integration of Palliative Care
5 minutes	Debrief

Learning Objectives

- Identify elements of palliative care that are most important to the care of individuals with sickle cell disease, which of these are already present, and which are poorly developed or absent
- Identify opportunities for further integration and expansion of palliative care in the care of those living with SCD

Show Video: Integration of Palliative Care (12 minutes)

Module 9

Navigating the Hard Times

Description

“Navigating the Hard Times” focuses on identification of sources of pain, suffering, and resilience in patients, caregivers, and family members affected by Sickle Cell Disease.

Time Estimate

75 minutes

Structure

5 minutes	Introduction
7 minutes	Show Film 4: Navigating the Hard Times
3 minutes	Individual Reflections on Film
55 minutes	Group Discussion
5 minutes	Application to Self and Home Institution

Themes

- Pain and Suffering
- Caregiver Resilience

Learning Objectives

(Refer participants to Learning Objectives for this Small Group that can be found in their Participant Notebook)

- Identify the range of challenges experienced by patients living with SCD that are commonly discussed and those that are often overlooked.
- Discuss the sources of resilience for patients living with SCD.
- Explore how the principles of palliative care can address physical and emotional pain experienced by patients and their family members
- Identify ways that resilience can be cultivated in patients living with SCD.

De-brief Plenary (5 min)

Decision-Making Plenary

- What new insights did you gain from the Plenary on decision making?
- How might you apply the decision making tool to your clinical practice?
- What lingering questions do you have?

Show Film #4: Navigating the Hard Times (~7 min)

Individual Reflection (3 min)

- What are your initial responses to this film? What surprised you?
- What did you notice about your feelings, body sensations, thoughts,? What do these tell you about yourself?

Group Discussion (55 min)

Ask participants to give short answers to the following question and write down the ideas on a flipchart.

- What is the meaning of suffering?

There are many definitions of suffering. According to Reich, suffering is “an anguish experienced as a threat to our composure, our integrity, the fulfillment of our intentions, and more deeply as a frustration to the concrete meaning that we have found in our personal experience.” (Reich, 1989). Eric Cassell describes suffering, “the state of severe distress associated with events that threaten the intactness of person,” as happening to the whole person who ascribes to it his or her personal meaning (Cassell, 1991, p. 33).

- How do these definitions align with your thoughts about suffering?
- What is the meaning of suffering to the patients? Families? Clinicians?
- What are the sources of suffering? Use the flipchart below to record answers from the group. (**Facilitator Note:** Possible examples in the film include:
 - (Nadia) “People feel like it’s something they’ve done”
 - (Miracle) “Why do I have to be sick?”
 - (Jeff) “Makes you feel sick when you’re not able to do what you’re trying to do” “you almost dread rounding on patients you know you aren’t helping”)

Sources of Suffering

	Physical Suffering	Emotional Suffering	Spiritual Suffering	Other Suffering
Patients				
Families				
Clinicians				

- Which of these sources of suffering are typically talked about and acknowledged to patients? Parents/family? Professional caregivers?

Many people distinguish pain from the meaning people assign to the experience. Alleviating suffering involves a whole person approach. First to treat the physical pain and then to address the sources of suffering that reflect the “story around the pain.”

- Which of these (or other) sources of suffering may often be overlooked or unexamined for patients, parents, and siblings?

(Facilitator Note: Possible overlooked issues or “stories around the pain” include: discrimination, race, class, ethnicity, depression, fatigue, immune system (frequent illnesses), how to get back to the rest of one’s life in terms of school, intimacy, etc.))

- How might discrimination contribute to physical and emotional pain?
- How do we help alleviate suffering?

(Facilitator Note: Possible responses may include:

- Structural social support: (Miracle) “Friends and family help me cope.”
 - Activities to quiet the mind and emotions such as meditation, yoga, reflective activities
 - Connection to nature
 - Physical activities
 - Distraction: (Miracle) “Walk with my ipod.”
 - Use of expressive techniques such as art, music, writing etc
 - Spirituality: (Miracle’s mother) “I pray a lot, nothing I can do, just be there.”
 - Engage the person’s inherent resilience and inner capacities)
- What does it mean to ‘fight’ pain? (Acceptance vs. surrender vs. fighting)

(Facilitator Note: Quotes from the film include:

- “You can’t fight this pain; you just have to cope with it.” “It’s not easy to relax when you’re in a lot of pain.”
 - “Relax, fighting pain makes it worse.” (Davon’s brother)
 - “You don’t need to be angry; you just need to deal with it.” “Being angry was getting me nowhere” (Miracle))
- How do you respond to Miracle’s comment about her day to day coping with a pain level of 6?
 - What does it suggest about her ability to deal with her situation?
 - What is the role of mental health and behavioral therapies in treating suffering?

(Facilitator Note: Refer to Miracle’s statements about mental health treatment for depression: “I don’t feel like myself because of pain and depression.” “Therapy is an outlet.”)

Resilience

- What does resilience mean to you?

There are many definitions of resilience; generally it refers to an individual’s capacity to be able to flow with the ups and downs of life. It involves an individual’s ability to manifest adaptive positive coping strategies that are matched to the situation while minimizing stress or distress (Mallack, 1998).

- What are the qualities of resilience?
- What examples of resilience do you see in the film?

List a few for patients, family members, and clinicians on the flip-chart using the following table as a guide:

Resilience

Patients	Family	Clinicians

- How can we support a person’s inner resilience?
- What is the role of mental health services in supporting the resilience of patients with SCD?
- What is the role of spirituality in supporting patient’s resilience?
- What are some other ways we could support the patient’s resilience?
- What role can palliative care play in addressing physical and psychological pain?

Application to Self and Home Institution (5 min)

- Regarding what we have discussed during this group, what change would you like to see/make at your home institution?

Agenda items: Refer participants to their agenda, noting there is a 15 minute break following this small group session before their second Team Meeting. Also remind them of the evening activity on Caregiver Well-being.

Module 10

Transitions

Description

This module discusses the difficulties presented by the complex transition between pediatric and adult care for adolescents with Sickle Cell Disease.

Structure (90 minutes)

5 minutes	Debrief Plenary
7 minutes	Show Film 4: Transitions
3 minutes	Individual Reflections on Film
70 minutes	Group Discussion
5 minutes	Application to Self and Home Institution

Themes

- Health system challenges, including lack of continuity
- Challenges in transition from pediatric to adult care models
- Adolescent empowerment

Learning Objectives

(Refer participants to Learning Objectives for this Small Group that can be found in their Participant Notebook)

- Identify common challenges for adolescents living with SCD as they transition to adult care
- Explore the relationship of stress, grief and uncertainty on the transition process
- Discuss ways to support adolescents in the transition from pediatric to adult care

Debrief Plenary (5 min)

Art Activity and Transition Plenary

- *(If applicable)* What stood out for you regarding the Art Activity?
- What stood out for you regarding the Transitions plenary?

Show Film #4: Transitions (~7 min)

Individual Reflection (3 min)

- What are your initial responses to this film? What surprised you?

- What did you notice about your thoughts, feelings, body sensations? What do these tell you about yourself?

Group Discussion (70 min)

- What are your responses to the transition we saw in the film?
 - Is it realistic? Sustainable?
- What were the emotional responses of patients in the film when they need to transition?

(Facilitator Note: Emotional responses of patients in the film include:

- Abandonment: (Shanta) “I went from feeling really taken care of to feeling like a chick in a big city”
 - Apprehension/Fear: (Miracle) concern about new system and how it works
 - Learning to be an adult, self-advocacy (Shanta)
 - Grief: Fear of losing important relationships, decline in functioning etc.)
- What are the emotional responses of patients when they need to transition at your institution?
 - What are the emotional responses of family members?
 - What does your institute do to transition patients from pediatric to adult care?
 - At what age are they transferred?
 - Do you transfer all patients at that age or only certain patients?

(Facilitator Note: Sometimes clinicians hold on to ‘good patients’ and pass on the ones they think are difficult.)

- What are the differences between your pediatric and adult care clinics?
- As a clinician, what is your perspective on transitions?
- Are your feelings positive or do you have reservations? (Prompts:
 - Letting go, grieving losses, like “losing a family member” (Jeff)
 - Attachment to children “Just like being a parent” (Kim))
- Do you think your attitude towards transition affects patient perspectives of transition?
- What is the relationship of stress, grief and uncertainty on the transition process for patients, families and clinicians?
- What are some ways these issues could be addressed more effectively?

Consider drawing the following (or similar) on flip-chart to help guide discussion.

	Stress during Transition	What is needed?
Patients		
Family Members		
Clinicians		

- How can we change from making transition seem impossible, to making it seem normal and demystify it?
 - What about anticipatory guidance for the process?
 - When to begin making the transition?
- What system issues contribute to the challenges experienced by adolescents transitioning from pediatric to adult care?
- How do we change the way the system is viewed while also acknowledging the systems (e.g. billing, lack of adult clinicians) gets in the way?
- What role can palliative care play in transitioning child to adult care?

Application to Self and Home Institution (5 min)

- Regarding what we have discussed during this group, what change would you like to see/make at your home institution?
- Discuss how perceptions of how transition could go better at your institution (in terms of changing the structure of care, etc.) and how you can facilitate adolescents make a successful transition.

Module 11

Moral Angst: The Heartache of Healers

Description

This module is designed to explore the internal responses (moral, emotional and spiritual) of clinicians who care for children with Sickle Cell Disease as they confront intense suffering and moral angst. Often unrecognized, these responses have a profound impact on the clinicians themselves, their interactions with patients, families and their colleagues.

Structure (~95 minutes)

5 minutes	Introduction
11 minutes	Show Film 6: Moral Angst: The Heartache of Healers
3 minutes	Individual Reflections on Film
70 minutes	Group Discussion
5 minutes	Application to Self and Home Institution

Themes

- Sadness
- Helplessness/ Frustration
- Betrayal/Anger among Professionals
- Vulnerability/ meaning

Learning Objectives

- Appreciate the importance of moral, emotional, and spiritual reflection for clinician well-being.
- Acknowledge the interplay between clinician well-being and the care of patients and families.
- Identify personal and professional challenges in appropriately caring for patients and family members during times of intense suffering.
- Develop awareness of one's common responses to patient/family suffering and our own
- Apply selected strategies to cultivate clinician resilience.

Show Film #6: Moral Angst: The Heartache of Healers (~11 minutes)

Individual Reflection

- What stands out for you in listening to these professionals discuss their experiences?
- As you think about the participants responses, which comments do you identify with and why?

(Facilitator note: Participants can write their responses or reflect silently.)

Group Discussion

Sadness

A frequent emotion experienced by clinicians but rarely discussed is sadness:

A pediatric hematologist says: *“What I see families go through and kids go through with chronic illness and the lives they sometimes end up leading compared to the lives, aspirations, and hopes I have for my own daughter, that makes me very sad a lot of the times when I’m seeing children that aren’t doing well.”*

- Have you ever been surprised by your emotions for a patient? What does this mean for you?
- How does working with patients whose quality of life is compromised affect you? (Prompts: Sad, helpless, hopeful, inspired, etc.)
- What other feelings are not openly discussed in our work with patients with SCD?

Helplessness and Frustration: Patient care

- Reflect on your experiences in caring for patients with SCD and their families when you have experienced helplessness.
- What feelings do you associate with this memory? What did you notice yourself saying or doing in response to these feelings? (Prompts: anger, shutdown, abandonment, numbness, disrespect, frustration, feeling inadequate or ineffective etc.).

(Facilitator note: Share the experience in a writing reflection, in dyads or small groups.)

- What do you do with feelings of helplessness towards your patients/families?
- How might this affect your care of patients/families or how they perceive you?

A common refrain by clinicians who are feeling helpless is: *“Why are we doing this?” “Should we be doing this?”*

- When you hear yourself or your colleagues saying these words, what do think underlines these statements? (Prompts: *Is your sense of right and wrong or your integrity as a person and a professional being threatened? Is your professional identity as a “good” nurse, doctor or other clinician being undermined? Are you being complicit in what you perceive to be moral wrongdoing?*)
- What are some ways you could address these feelings—individually or as a team?

In the film, clinicians often communicate their sense of helplessness by referring to it as “frustration”.

One source of frustration refers to **patient’s lack of progress**.

A nurse says: “Working in the infusion center 5 days Monday – Friday 9-5 and dealing with the population we do with SCD it does come to a point where frustrating really is the best word that you can use. You feel sometimes there’s no progress.”

Another source of frustration relates to **ineffective communication**.

Adult hematologist: “When I felt [frustration] the most is when I thought I communicated what I wanted to communicate, but what I communicated didn’t get heard... that’s the time you feel least adequate.”

A third source of frustration is **when progress is “undone” by families**.

Pediatric hematologist: “Sometimes you feel like you’re trying to do everything right and think you’re on the road to helping a child and sometimes things do get undone by families. You just feel helpless.”

- In the clinician quotes above, what is the source of their helplessness/frustration? (Prompts: Distinguish between frustration at not being able to cure or effectively treat the disease and the frustration about the impact of social factors of the patient/family that impact the perception of progress.)
- To what extent are these kinds of experiences familiar to you?
- How do you respond:
 - When there is lack of progress of your patients?
 - When communication is ineffective?
 - When the family members of patients seem to complicate the provision of recommended treatment?
- How do you remain mindful of the social issues that impact your patient’s ability to follow through with proper treatment?
- Are there other sources of helplessness or frustration have you experienced in the care of patients with SCD?
- Share an experience where you have felt helpless or frustrated in the care of patients with SCD. As you do so, notice what feelings arise.
- On a piece of paper, jot down a few words or phrases: What might you say to your patient or colleagues about your frustration? What might you do in response to your frustration?
- What do you notice about your responses?
- How do keep negative feelings about patients or patient’s family members from affecting your ability to remain empathic or responsive to their needs? (Prompt: How have these experienced impacted your own well-being/quality of life?)

Anger/Betrayal Among Professionals

- Think of a time when an interaction with a colleague or colleagues caused you to feel negative emotions. What specific emotions arose in you in response to this situation? (Prompts: felt angry, disrespected/disregarded, judged, unappreciated, betrayed, etc.).
- How did you respond to these feelings? (Prompts: lashed out at the person, lashed out at others – including family members, gossiped, cried, felt resigned, shutdown, etc.).
- Share the experience in a writing reflection, in dyads or small groups.

In the film, clinicians refer to several types of intercollegial interactions that resulted in negative emotions. One type of negative interaction occurs when other clinicians or ancillary staff criticize or negatively judge your actions.

Sophie: *“If I get a call from a patient at an outside facility from a patient who wants guidance and the doctor recommends a treatment I completely disagree with, I can have that conversation and be completely ignored. I think that’s disrespectful. Being treated with a lack of respect for your knowledge and opinions happens more to women physicians than it does to male physicians. It’s hard to put into words, but this feeling of ‘Oh, it’s Dr. Lanskrone. She has no spine and lets them walk all over here. She gives everyone pain medications.’ There’s that idea that it’s not thought of highly to do what I do for a living...”*

Jeff: *“Some of the only negative interactions I’ve had are with ancillary medical staff. People having different opinions about how they should be treated. From one perspective it looks like the thing to do is kick the kids out of the hospital, they’re malingering. It has been insinuated that I’m a bit spineless at times... ‘I can’t believe you’re letting them stay overnight again.’”*

- Feeling judged as “spineless” or having your competence questioned can lead to feelings of anger. To what extent are these kinds of experiences familiar to you?
- Have you experienced them personally or witnessed colleagues make or receive negative judgments of others?
- To what extent are these negative judgments related to the colleague’s gender, age, or ethnicity?
- Are there assumptions about patients with sickle cell disease that may be projected onto their caregivers? To what extent do you feel like your colleagues negatively appraise the patient population that you care for and, by extension, judge your care of them negatively? What impact does this have on you?

Another source of negative emotions occurs **when you judge colleagues as incompetent, uncaring or neglectful.**

Sophie: *“You hear the same story again and again, person went to ER, took labs, told the patient they weren’t in crisis. Although some of it’s frustration, it’s more anger because I think those providers*

should know better... although maybe my expectations are set too high. Even if you don't see sickle, you pick up the phone, you call for help, you ask. It's ok not to know, but it's not ok to ask for help. That angers me."

Vickie: "My anger as far as colleagues go is more so when I'm either receiving a patient from another department or transferring to another department. I've gotten reports in the morning and they say 'he hasn't had a dose for 3 hours'. Why? 'He hasn't gotten his long-acting.' Why? It's more so anger where I clearly see a patient was neglected."

- To what extent are these experiences familiar to you?
- Have you ever found yourself negatively judging your colleagues? If so, what impact has this had on your own sense of well-being? (Prompts: I don't want to come to work, I avoid interactions with those individuals, I isolate myself, I feel irritable all the time, I talk negatively about others when they are not present, etc.)
- To what extent is there a tendency to make negative judgments about colleagues who occupy other roles or come from other disciplines, departments or institutions? What might contribute to this pattern of behavior?
- One of the underlying themes of these quotes is the issue of respect between colleagues. How would you describe respect in collegial relationships? On a piece of paper, jot down a few words or phrases that reflect behaviors that you associate with respectful interactions. What do these words or phrases suggest about how to cultivate respect?
- What is the impact of negative emotions on respect? (Prompts: when I feel betrayed, my trust is broken. When I no longer trust, I am less likely to cooperate, more likely to point finger and blame, more likely to create work-arounds, etc.)
- What is the impact of disrespect and other negative emotions on team functioning and communication?
- What could be done, whether personally, within your team, within your institutional culture, or between institutions, to strengthen respectful behaviors among colleagues?

Vulnerability/Meaning

One of the consequences of strong negative emotions like anger, betrayal and disrespect is the awareness of one's own vulnerability. Because clinical training emphasizes and rewards expertise and confidence, it is very difficult for clinicians to acknowledge their vulnerability.

- Reflect on the situations in your own clinical practice that activate feelings of vulnerability.
- Share one such experience in a writing reflection, in dyads or small groups.

In the film, clinicians refer to the impact of vulnerability on their own well-being:

Jeff: *“You feel despite your best efforts the child isn’t doing as well as he or she should and it’s out of your control. I tend to dwell on those a bit and do feel guilty about things that don’t go right even if they weren’t under my control. So maybe as vulnerability laying in bed at night thinking over and over again of how I should have done that differently... I can get a little down during the day... especially when things aren’t going well.”*

Sophie: *“I think all clinicians worry about their patients and well-being. There are lots of nights I’ve not gotten good night’s rest because I’ve worried if my patient will make it through the night.”*

- In what ways have your own experiences of vulnerability affected your sense of personal or professional well-being?
- How might you be able to engage more positively with your own vulnerability and use it as a resource for enhanced quality of interactions with patients and colleagues? What would need to be in place personally or professionally to support this shift?

One of the antidotes to negative emotions (whether toward colleagues or patients) is to remember why you have chosen to care for patients with sickle cell disease.

In the film, clinicians refer to two sources of meaning in the care of patients with sickle cell disease:

Jeff: *“Having children able to overcome their illness and go on and have productive wonderful lives is something I’m always striving for. Taking kids who are having trouble and being able to work through that trouble and getting them back on track. I think that’s the most rewarding part of it...”*

Sophie: *“I enjoy the conversation and hearing about their lives and trying to solve the everyday sort of challenges they have... Everyday is a struggle and so the social issues of being able to get a job, keep a job, get food on the table, making sure there’s someone to take care of the kids when you’re in the hospital. All those social aspects become part and parcel of what I do everyday.”*

- What gives you meaning in caring for patients with sickle cell disease and their families?
- Pause and reflect on the moments you have experienced that strengthen your resolve to continue in this work.
- What intentional strategies or rituals might you use to remain connected to your sense of meaning in your work and use it as a resource for enhanced quality of interactions with patients and colleagues?
- In reflecting on your overall experience in completing this module, what has it been like for you to discuss the impact caring for patients with SCD has on your personal and professional life?

Application to Self and Home Institution:

- Regarding what we have discussed during this group, what change would you like to see/make at your home institution?

Exercises

Listening

Interactive Exercise (60 minutes)

1. The facilitator invites participants to find a partner-preferably someone they do not already know.
2. Have the partners face each other.
3. Determine the order that each person will speak.
4. Each person will have 3 minutes to share his/her responses to a question.
 - a. The question to be explored: “Share a time when you were able to provide care for a patient with SCD that you were proud of.”
5. The first person to speak will share their experience while the other person listens **silently**. There should not be any cross talk or questions during the time the person is speaking. The listener is invited to bring their whole self into the process and listen deeply to the words of the other person.
6. At the end of 3 minutes, the facilitator will signal the end of the time. The person speaking should complete their sentence and both people remain silent.
7. The roles switch and the listener, becomes the speaker and the speaker listens deeply in the same way as their partner.
8. At the end of the second 3 minutes, the partners will thank each other.

Debrief

Speakers:

1. What was it like for you to speak about your experience in this way?
2. What did you notice in your body, emotions and thoughts as you told your story?
3. What was it like to be listened to by your partner?
4. What did you notice that suggested to you that they were listening to you?

Listeners:

1. What was it like for you to listen to your partner?
2. What did you notice in your body, emotions and thoughts as you listened in this way?
3. What did you notice yourself wanting to do or say?
4. What was your experience of being silent?

Images of Hope

Interactive Exercise (60 minutes)

Group Activity

Supplies:

Provide a collection of images (postcard size works well) that evoke different feelings drawing from nature, art, photographs, and other scenes. Provide an ample supply of images so that there are about twice as many images as the people in the group so that there are plenty to choose from.

Prep: Arrange chairs in a circle. Place the pre-selected images on the floor in the center of the circle. Invite members to sit in the chairs in the circle. Place one page of flipchart paper on the wall near the circle. Have tape and post-it notes nearby.

- Invite group members to sit quietly for a moment. When everyone is settled, begin with the first person in the circle; invite them to choose an image from those in the center of the circle that represents hope to them. Each person goes in turn until everyone has an image.
- In silence, ask participants to reflect on their chosen image for 1-2 minutes.
- Go around the circle and ask each member to share in 1 sentence share what this image means to them.

(Facilitator Note: *Encourage participants to distill their statements to just once sentence. Example: “This image of mountains represents hope to me because...”*)

- After each person has spoken, pause for a moment and ask group members to briefly reflect on what they have heard from each other.
- Pass out Post-it notes to each participant. Ask them to write one word that represents hope to them (can be related to the image or another word).
- Ask each participant to tape their image and their post-it note word (which they share with the group) onto a flip-chart, creating a group collage. The post-it note can be placed on the collage – either on their photo or somewhere of their choosing.
- When everyone has placed their image and post-it note on the group collage, invite everyone to stand together in front of the collage to reflect on the image and what it evokes for them.
- End the session with a moment of gratitude to everyone for their participation in the activity.

Exploring Quality of Life

Interactive Exercise (60 minutes)

Format:

10 minutes	Introduction
20 minutes	Group Introductions
3 minutes	Individual Reflections on Quality of Life
7 minutes	Discussion in Pairs
20 minutes	Group Discussion

Introduction (10 minutes)

- Your role in this session is facilitator. Welcome participants. Explain the rationale for the emphasis on small group learning across boundaries (i.e., family member/clinician, different disciplines and settings of care).
 - (Refer to *Relational Learning* article on Related References sheet in Participant Notebooks. Facilitator's have one copy of this article to offer to small group participants if they did not have a chance to read the article e-mailed to them ahead of time.)
- Explain that this is the first of six sessions in which the small group will meet:
 - Sessions 1b, 2, 3, and 4 will use small group activities from the curriculum.
 - Sessions 1a and 5 will introduce and close the group's work together.
 - (Refer to Retreat Agenda in Participant Notebook)
- Review general guidelines and groundrules for small group work.
 - (Refer to Participant Notebook for "Responsibilities for Collaborative Learning,")
- Discuss self-awareness, reflective practice, creating safety, vulnerability, taking risks.
- Introduce yourself and the facilitator briefly and review your role as faculty, facilitator, debriefers, and guides.
- Review Learning Objectives of this session: (Refer participants to Learning Objectives for this Small Group that can be found in their Participant Notebook)
 - Recognize the range of individual perspectives on what constitutes "quality of life"
 - Explore the role of palliative care in discussing quality of life for patients and family members
- As you facilitate this session, do your best to make family members in your group comfortable taking part in the discussion. Look for opportunities to draw them into the conversation.

Group introductions (2 minutes per participant, 20 minutes total)

- Explain that the remainder of this session will be devoted to exploring basic values regarding quality of life. Ask each person to introduce themselves in the following way: Please state your name, discipline or role (physician, nurse, family member, etc.), and home institution. Then, please respond to the following question. Ask each person to "distill" their comments into 2 minutes (you will need to monitor the time).

“Please respond to the following prompt, keeping your responses to approximately 2 minutes. Question: The most important thing I have learned in caring for children with life limiting conditions, such as Sickle Cell Disease, is...”

Individual Reflections on Quality of Life (3 minutes)

Ask each participant to take 3 minutes to individually reflect and write answers to the following questions:

1. If you were defining “quality of life” for yourself and/or your family, what 5-6 components would be most important?
2. What *values* underlie your definition of quality of life?
3. When you were an *adolescent*, what meant the most to you regarding your quality of life? Now, think of being a patient with SCD. Would you have been able to experience these things?
4. What would they need to be able to achieve your desired quality of life?

Group De-briefing and Discussion (25 min)

1. What is the “essence” of quality of life? Ask participants to list some of their components of Quality of life –use a flip chart to capture the list
2. Facilitator Note: Use some of the following questions to probe meaning of quality of life.
 - What do you notice about the similarities or differences in your responses about quality of life?
 - How do they compare to what you’ve heard from patients and their family members? What key components/values seem to be critical in defining “quality of life” for a child with disabilities, especially those with SCD?
3. What is the role of hope in quality of life?
4. How can you, as a clinician, help adolescent patients increase their quality of life?
5. How can patients, families, and clinicians have productive and comfortable conversations about definitions of quality of life and the implications for treatment?
6. How might discussion of palliative care contribute to those conversations?

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Exploring Grief, Meaning, and Self-Care

Art Activity

(60 minutes)

Background

All participants will engage for 30 minutes in an open-ended art exploration around the theme of grief, meaning and self care. After this process, participants will process their experiences and thoughts as facilitated by faculty leaders.

Exploration of Themes (45 minutes)

Ask participants to share their artwork -- as a product and as a process -- using the following questions to facilitate discussion:

- 1) What was your experience in the art process?
- 2) What images arose in your art process?
- 3) What ideas or feelings did you experience symbolically or concretely in your art process?
- 4) What ideas or feelings do you experience now looking at your artwork around the themes of grief, meaning and self care?
- 5) How does a nonverbal process like art-making inform us regarding the themes of grief, meaning and self care?
- 6) What are the implications of these ideas for communication and partnership with children and families affected by life-threatening pediatric disease?

Note that there are no correct answers to the processing in this discussion. Participants can be encouraged to share their artwork with the group and discuss their experience in both creating the piece and exploring it relative to the themes of this session. Suggestions for facilitation will be discussed in onsite faculty meeting.

Overall Debriefing (15 minutes)

Ask participants, "How might the kind of learning from this session happen in settings -- both formal and informal -- within your own institutions (e.g., educational activities, rounds, nursing report, lunchtime conversations, family meetings, staff meetings)?"

Closing Activity

(50 minutes)

35 minutes Group Activity/Discussion
10 minutes Overall Debriefing

In this session you will guide the small group members to complete their experience together. For many participants, the experience of learning in a small group setting may have been quite different from other professional learning experiences. This session is an opportunity for people to reflect on their experience and say their “good-byes” since this will be the final small group session.

Materials: *Shells, dish, retreat evaluations*

Introduction and De-Briefing of Art Activity and Transition Plenary (15 minutes)

- What did you notice about your responses to the art activity? What did you learn about yourself and others?
- What new insights did you gain from the transitions plenary? What opportunities do you see to enhance the experiences of adolescents in their various transitions?

Group Activity/Discussion (35 minutes)

Thank participants for their involvement in the group.

Make a few remarks about your own experience in the group and what it was like for you to serve as faculty and facilitator.

Ask each participant to share what it was like to participate-what surprised and/or inspired them from the retreat. (Hopefully all will do so.)

Ask each person to consider what others can count on them for when they go back to their home institution regarding palliative care. Ask them to write a word that reflects this commitment on a post-it note. Ask them to bring the post-it note into the final session.

Finally, place the shells in a dish and send them around to each group member. Invite them to take a shell from the dish and tell them it will be a tangible reminder of the time here-the people they met, the vision shared, the creative ideas that arose.

Instruct them to take a shell and respond to the following:

- How will you practice differently as a result of being here?

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Appendices/Supplemental Materials

Team Meeting #1

Facilitated by Faculty/Facilitator

(60 minutes)

When using a longer version of the curriculum and one of your goals is to leverage the training for organizational change, we have included opportunities for inter-professional teams to work together. The following are suggested formats for those team meetings to help structure a process aimed at creating an actionable plan to leverage change.

Vision of Hope faculty and facilitators will serve as facilitators for the first team planning session, with a focus on concrete challenges in applying and implementing what has been learned at the workshop back at home institutions. Note that your group will be comprised of one institutional team and parent(s).

Overview of purpose of team meetings

The outcome of this process at the end of the retreat is for each institutional group to develop a commitment statement that reflects their guiding values, principles, and commitments to improving the lives of children with SCD and a beginning action plan for integrating palliative care into pediatric SCD care.

During this initial team planning session, direct participants to the *Next Steps* worksheet in their Participant Guide. Explain that, throughout the retreat, references will be made to instituting change “back-home.” The worksheet is a tool for participants to use in organizing their ideas.

Facilitator will guide the discussion. Ask for a volunteer to be the scribe for the group’s discussions. Identify a person(s) from the group who will be responsible for the follow up and implementation of the groups’ plan after the meeting.

Introductions:

Introduce each person in the following way:

Name, discipline, role in the care of children with SCD, and one thing they would like to see changed to improve their care. (Brevity is beautiful—each person should limit their introduction to 3 minutes.

Group Question:

What is most important to you in the care that you provide to patients with SCD?

Have each person in the group say a word or sentence that answers this question. Have the scribe write these words or phrases down and read them after each person has spoken.

Current Status of Institution:

Invite people in the group to consider what they are currently doing in their own institution in integrating palliative and end of life care into the care of patients with SCD.

Make a list of things that are currently being done in the areas of education, clinical practice, protocols, policies, inclusion of parents and family members, etc regarding palliative care.

Goals of Institution:

Invite people to consider potential goals for their institution based on the thoughts of the participants and institutional culture and receptivity regarding palliative care integration with SCD. **These goals should be related to the themes of palliative care: Quality of Life, Decision-Making, Communication, Symptom Management, Psychosocial Support, etc.**

Example goals might include the following:

- 1. Develop ways to initiate educational activities at my own institution about the needs of children with sickle cell disease and the role of palliative care.*
- 2. Develop ways to better integrate family members as teachers and consultants in those educational activities as well as in other initiatives to enhance care for children and families affected by sickle cell disease.*
- 3. Continue to collaborate with colleagues within my own institution as well as regionally, nationally, and internationally to improve education and practice for children living with sickle cell disease and their families.*

Invite the group to write down 1-3 possible goals for themselves on their Team Meeting #1 worksheet (in participant guide).

Goal 1:

Goal 2:

Goal 3:

- Ask participants to keep thinking about ways to address these goals as they continue to attend the retreat and jot them down as they will continue this conversation during Team Meetings #2 and #3.

Team Meeting #2

Not facilitated by Faculty/Facilitators
(60 minutes)

The outcome of this process at the end of the retreat is for each institutional group to develop a commitment statement that reflects their guiding values, principles, and commitments to improving the lives of children with SCD and a beginning action plan for integrating palliative care into pediatric SCD care.

The person(s) identified from Team Meeting #1 as being responsible for the follow up and implementation of the groups' plan after the meeting can facilitate this meeting.

Work on Institutional/Organizational Next Steps

- Invite people to reflect on the goals for your institution discussed in Team Meeting #1 regarding palliative care integration with pediatric SCD care.
- Clarify the 1-3 goals your team will focus on upon returning to your home institution and write them below.
- Ask each team member to share ideas they have written down on their worksheets or have thought of throughout the retreat to address these goals and write them under the corresponding goal below.
- Keep in mind potential challenges/obstacles and suggest strategies for addressing the challenges/obstacles
- At the end of this session, each team should have a provisional list of goals that will be refined for final presentation in Team meeting #3.

Goals of Institution

Goal 1:

Steps for implementation:

- 1.
- 2.
- 3.

Goal 2:

Steps for implementation:

- 1.
- 2.
- 3.

Goal 3:

Steps for implementation:

- 1.
- 2.
- 3.

Team Meeting #3

Facilitated by Faculty/Facilitator
(60 minutes)

During this session, participants will refer to their *Next Steps* worksheet which they have previously filled out and discussed with their fellow team members.

Introduction (5 minutes)

- Explain that you will facilitate the session but will look to the group for their active participation.
- Remind participants that, throughout the workshop, references have been made to instituting change “back-home.” This breakout session will focus on this through discussion of their *Next Steps* worksheets.

Work on Institutional/Organizational Next Steps (20 minutes)

- Remind participants of the three areas on the *Next Steps* worksheet and their 1-3 goals they created in Team Meeting #1.
- Ask each team to share ideas they wrote down on their worksheets or have thought of throughout the retreat.
- Ask each team to consolidate these ideas into their 1-3 goals and identify potential challenges/obstacles in implementation.

Sharing Next Steps: Commitment Statement and Action Plan (20 minutes)

Commitment Statement

- Ask team to create a commitment statement that shares their intention as a team for when they return to their home institution. The commitment statement should include overarching ideas, values and guiding commitments the team will maintain in their work when they return home.
- Ask participants to suggest statements that reflect their commitments to improving the care of children with SCD through better communication, ethical decision making, quality of life, and end of life care. Reflect on what will you DO and how will you BE as a result of your work together over the last 3 days?

Action Plan

- 1) Ask team members to review the 1 – 3 goals and related action steps identified in Team Meetings 1 and 2 that they are willing to implement following the retreat to advance the integration of palliative and SCD care. Consider what is feasible and realistic for the next 6 months. Be sure to include ways to celebrate their successes.

Poster Creation (15 minutes)

- Ask the team to create a poster that reflects commitment statement and action plan.
- Each team will be given templates, a flip chart, and pens to develop their poster.
- Bring poster to main room for display.

Next Steps Worksheet

Throughout the duration of the retreat, we want you to think about specific ways in which you can extend your own learning to colleagues and others. We hope that all of you will take advantage of the new connections you have made at the retreat to network together over the coming months to improve care for children with sickle cell disease and their families.

The following outline allows you to organize your ideas and think about how to follow up on your ideas when you return to your home institution. During the Team Planning Sessions at the retreat, you will share your ideas about next steps with other participants and receive input from your colleagues.

Action Steps

Please list 2 – 3 specific actions/steps identified in response to the goals you created in Team Meeting #1 that **you are willing to implement following the retreat to advance the integration of palliative and SCD care in the following areas.**

Goal 1:

Action Step #1

Action Step #2

Action Step #3

Goal 2:

Action Step #1

Action Step #2

Action Step #3

Goal 3:

Action Step #1

Action Step #2

Action Step #3

Commitment Statement and Action Plan

Institution: _____

Commitment Statement/Oath:

Goal #1:

Action Step #1

Action Step #2

Action Step #3

Goal #2

Action Step #1

Action Step #2

Action Step #3

Goal #3

Action Step #1

Action Step #2

Action Step #3

Resources and References

Sickle Cell Disease

- Benjamin, L. (2008). Pain management in sickle cell disease: Palliative care begins at birth?. *ASH Education Program Book, 2008(1)*, 466-474.
- Edmonds, P. (2001). Sickle Cell Disease. In Addington-Hall, J. & Higginson (Eds.), *Palliative Care for Non-cancer Patients*. (126-136). Oxford: Oxford Scholarship Online.
- McClain, B. C., & Kain, Z. N. (2007). Pediatric palliative care: A novel approach to children with Sickle Cell Disease. *Pediatrics, 119(3)*, 612-614.
- Navaid, M., & Melvin, T. (2010). A palliative care approach in treating patients with Sickle Cell Disease using exchange transfusion. *American Journal of Hospice and Palliative Medicine*.
- Wilkie, D. J., Johnson, B., Mack, A. K., Labotka, R., & Molokie, R. E. (2010). Sickle Cell Disease: An opportunity for palliative care across the life span. *Nursing Clinics of North America, 45(3)*, 375-397.

Palliative Care and Other

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- The Conversation Project: Conversation Starter Kit
- The Education Development Center, Inc.
- Hays, R. M., Valentine, J., Haynes, G., Geyer, J. R., Villareale, N., Mckinstry, B., ... & Churchill, S. S. (2006). The Seattle Pediatric Palliative Care Project: Effects on family satisfaction and health-related quality of life. *Journal of Palliative Medicine, 9(3)*, 716-728.
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- IPPC: Family Members as part of the Interdisciplinary Team
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- Kuttner, L. (2010). *A child in pain: What health professionals can do to help*. Bethel (CT): Crown House Publishing Limited.
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