An Integrated Social Work & Art Therapy Program for Hospice and Palliative Care Patients who are Parents of Young Children

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Objectives

Upon completion of this educational activity participants will be able to:

• Provide interventions for young parents on palliative care and hospice
• Identify benefits of early anticipatory interventions
• Explore role of clinician in end of life care
Case Example

Terry, age 42, is a vivacious young mom, interested in photography and traveling. Married to Carl, age 42, for twelve years they are parents to Pipi, age 8 and Ava, age 10. Diagnosed with breast cancer, Terry endured multiple treatments for 4 years with only brief periods of remission. The girls grew up knowing illness, chemotherapy and the phrase “Mommy doesn’t feel good right now.” Weeks after a clinical trial ended, Terry experienced both liver and kidney failure. At that point they made the difficult decision to select home hospice.
Challenges

- Facing mortality at a young age
- Planning for the future and well-being of the children
- Achieving delicate balance of allowing parents to say goodbye to one another and their children.
- Simultaneously facilitating hope, stability and resilience
- Recognizing and dealing with counter-transference issues
Who Are The Players?

- Hospice/Palliative Care Team
  - Social worker
  - Art therapist
  - Chaplain
  - Nurse
- Multiple Clients
  - Patient
  - Spouse/caregivers
  - The Couple
  - Children
Role of the Social Worker

• Identify concerns of parents
  – Relationship as a couple
  – Children’s current coping
  – Children’s future
  – Legacy of parent to the children and to the spouse and possibly other family members

• Provide opportunity to express feelings and address concerns
Identify Goals for Each Client

- Patient: reinforce role as individual, wife and mother
- Spouse: forum to express frustrations, desires, hope for future
- The Couple: resolution of issues
- The Children: age appropriate language and coping tools
The Patient’s List

- Protect her children and spouse
- Grief re: inability to raise children
- Honesty and respect
- Resolution of relationships
- Facilitate hope for the future for spouse and children
- Who will take care of/nurture children?
- Not to be a burden
What Does the Spouse Want?

- Old life back
- Clear communication from MD’s
- Acknowledgement of multiple roles
  - Grieving loss of life partner
  - Caregiver
  - Single parent responsibility
  - Facilitating children’s grief and coping
- Hope for the future
What Does the Couple Need?

- Time or permission to still be a couple
- Facilitate life review
- Address successes and failures
- Validate feelings for one another, their children, their family
- Discuss goals for future
What Do Children Want?

• Honesty
• Respect
• Opportunity for self-expression
• Understanding
• Help them to hold on to happy memories

– Do you remember when....? This was her favorite food, etc.
Addressing the Issues

• Common Patient/Parent Fallacy:
  – “hiding information from children is the way to shield and protect them”

• Hospice/Palliative Care Experience:
  – “openness and honesty with children will give them the tools they need to cope”
  – Individual and family interventions to address needs of each client

• Terry: “I’m dying and I need to know how and when to tell my children.”
Psycho-Education

- Children may try to protect parents by not bringing up difficult topics
  - They know more than you think
  - Will mirror adult behavior
- Saying the “wrong thing”
  - It is ok to say “I don’t know”
  - Use specific concrete name of disease
  - Don’t say “Mom is sick or ill”
- Protecting child causes unnecessary anxiety and sometimes guilt
Tools to Use

• Listen attentively to discover children’s concerns
• Address, don’t minimize, fears and concerns to alleviate anxiety
• Use the word “dying”
• AVOID euphemisms
• Reassure children about who will care for them
When Is The Right Time?

- No one answer; rarely is there a “perfect moment”
- Explore and problem solve patient and spouse fears and concerns
- Provide tools: words, a script, “what to do if” scenario
- Seize the moment when they want to talk/ask questions

For Terry, the right time was when she had visible signs of decline.
Talking Points

- Develop with patient and spouse
- Consider age of children and perceived level of understanding
- Empower parents to involve children appropriately and honestly in end of life plans

Moments after sw, art therapist & chaplain last visit, Terry was able to speak honestly with her daughters about her impending death.
Essence of Helping Children

“The greatest gift you can give your children is not protection from change, loss, pain or stress, but the confidence and tools to cope and grow with all that life has to offer them.”

Harpham, 1997
Involve the Children

• Everybody can have an age appropriate role in caregiving
  – Getting fresh water to keep mouth moist
  – Talking about school day
  – Reminiscing
  – Hugs or physical touch as appropriate to the disease and pain level
  – Drawing or other art therapy interventions
How Do Children Cope?

- Experience multiple emotions simultaneously
  - Sadness, anger, happiness when playing with friends
- Ask direct questions
  - What does a coffin look like? Isn’t it cold and dark down there?
Anticipatory Grieving

- Integrating/updating children during the illness phase leads to better coping skills during bereavement
- Tone during hospice sets the tone for bereavement
- Preparation during hospice also has implications for surviving parent
- Let children know/see you are mourning
Coordinating with the Hospice Team

- Speak with the nurse case manager and other team members frequently
- Use team communication tools (voicemail or written) to keep everyone informed of status changes
- Support one another; it is easy to identify with young families
Role of the Art Therapist

Multiple Family members all grieving differently

Goal: Greater state of well-being for all

Enables the expression of what is often inexpressible

Guides/supports the children, meeting them where they are at, and taking cues from the parents’ stance on what has been discussed thus far.

Well-being provided for the family becomes part of the repairing process long after the patient has died.
Art Therapy Interventions

Create customized coping tools for each child so they build an arsenal of self-soothing techniques that work:

-- for the moment
– for the duration of the illness
-- for future events.

Art allows children to express their feelings and build hope as they use their imaginations.
Art Therapy with Terry’s Girls

Ava, 10 years old “guarded and shy”

Pipi, 8 years old “vivacious and talkative” wanted to look inside the art therapist’s bag of supplies right away!!

Being sensitive to both children’s needs is paramount to making that first introductory session a positive and safe one for both children.

ART THERAPIS RULES:
---carry art supplies that are always in good condition
-- include colored pencils, magic markers, some crayons and pastels
--heavyweight paper is also advised.
The art that is created in art therapy can act as a witness to what happens in life, whether it be tragic or radiant, horrifying or beautiful.

3 Goals of Terry’s Script

- Hearing what she wanted to do and ensuring that it could happen gave her back some control, even in the dying process.
- Terry was the creator of the piece, and being a photographer she was afforded an opportunity to create one final creative piece.

Finally, her thoughts and her wishes for her children were immortalized on paper. (Terry dictated what she wanted to say based on the conversations between herself, her spouse, the social worker and the art therapist)
After Terry’s Death

Extremely important that the art therapist stay visible and provide follow-up visits.

The children only met the art therapist twice prior to death event.

Let the children actively steer the bereavement process.

Proceed at a gentle and slow pace; children have gone through tremendous stress and sadness.

Asking them how they feel about the loss at each session only re-traumatizes them.

Do not force children to talk about their feelings. Instead, let the art directives tell the story.
The surviving parent can and should participate in some art activities with the children.

Art therapist brought ceramic pots for Carl and the girls to paint together.

Certain traditions may remain in family but it is ok for new ones to begin.

Mother’s Day will never be the same but each year the surviving parent and the children can do something to honor Terry’s memory such as paint a clay pot or mosaic stepping stone.
TERRY’S LEGACY

Find that magical place in your world... and live there. “May you have moments of joy and happiness. Moments of stillness and daydreaming. Moments of closeness and love.”


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