Caring for Cancer Patients with Children

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Disclosures

No Conflicts of Interest

Learning Objectives

Participants will be able to:

- Summarize literature review of parents diagnosed with cancer and impact on their family.
- Identify distress and needs of parents with cancer
- Apply information to provide resources and initial support for patients with children

Literature Review

Cancer and Parental Status Statistics

- 18.3% patients newly diagnosed with cancer have at least one child <18 years old
- 1.58 million U.S. cancer survivors live with minor children which is approximately 2.85 million children
- Every year an estimated **55,000 children lose a parent to cancer** in the U.S. (Weaver et.al., 2010)
- Institute of Medicine report on Breast Cancer identified parenting guidance and psychoeducation as a gap in recommended care (2004)

Parents with Cancer

Cancer and Parental Status Associated with:

Higher:

- **Anxiety and worry compared to non-parent cancer patients** (Nilsson et al., 2009)
- **depression** (Johannsen et.al., 2021;Park et.al, 2016; Park et.al., 2016, Schmitt et al., 2008)
- **For patients with metastatic cancer parenting concerns primary predictor of anxiety and depression** (Park et al., 2019)

Decreased:

- **quality of life, particularly at end of life** (Park et.al, 2016; Park et.al., 2016, Nilsson et al., 2009,Schmitt et al., 2008)
- **decline in parenting efficacy** (Moore et al., 2015; Gotze et al., 2015; Stenberg et al., 2010)
- **peacefulness compared to non-parent cancer patients** (Nilsson et al., 2009)

Patients with advanced cancer **preferring aggressive treatment over palliative care and less likely to initiate advanced care planning** (Yellen and Cella, 1995; Nilsson et al., 2009)

Parents with Cancer report:

- **Concerns regarding impact of cancer on young families** (Muriel et al., 2012)
- **Worried about inability to parent due to illness, symptoms, treatment side effects and physical limitations** (Muriel et al., 2012; Helseth & Ulfsaet, 2005; Moore et al., 2015)
- **Feeling inadequate on how to effectively communicate with their children regarding cancer diagnosis, particularly if one experiences recurrence or progression of disease** (Walczak et.al., 2018; Moore et al. 2015; Semple and McCaughan, 2013; Semple and McCance, 2010; Northouse et al, 2002; Park et al., 2019)

Parents with Cancer report:

- **Advanced cancer patients concerned how death will impact children** (Muriel et al., 2012; Park et al., 2016; Park et al, 2019; Park et al., 2017)
- **Needing family-specific psychosocial support for selves as a parent as well as for partner and children in addition to help with practical needs** (Inhestern et al., 2021)
- **Parenting concerns not addressed by oncology providers despite wanting advice and guidance** (Semple & McCance, 2010; Semple & McCaughan, 2013; Rauch & Muriel, 2004; Arber & Odelius, 2018)

Spousal Caregivers of Cancer Patients with Children

Spousal Caregivers with children Associated with:

Higher:

- **Anxiety**
- **Depression compared to counterparts with no children** (Finocchiaro et al, 2012; Pelletier et al., 2002, Northouse et al., 2002; Park et al., 2019)
- **Complicated grief** (Nilsson et al., 2009)
- **More likely to develop major depressive disorder and generalized anxiety disorder** (Nilsson et al.,2009; Braun et al., 2007)

Decreased:

- **Quality of life** (Borstelmann et al., 2022; Park et al., 2019; Finocchiaro et al, 2012; Pelletier et al., 2002, Northouse et al., 2002)
- **Decline in parenting efficacy** (Moore et al., 2015; Gotze et al., 2015; Stenberg et al., 2010)

Spousal caregivers/coparents tend to experience substantial distress due to the competing tasks of caring for their ill partner as well as their child(ren) (Moore et al, 2015)

Children of Cancer Patients

Children of Parents with Cancer report:

- **Parents underestimated impact of cancer on their children** (Morris et al., 2016)
- **Significantly impacted by their parent's cancer diagnosis** (Faccio et.al., 2018; Morris et.al., 2018; Walczak et.al, 2018; Morris, et.al., 2016; Visser et.al., 2004)
- **Significant emotional problems, worries, confusion, and loneliness in response to a parent's cancer diagnosis** (Morris et.al, 2018; Moller et.al, 2014; Karlson et.al., 2013; Visser et.al., 2004; Zahlis, 2001; Gazendam-Donofrio et.al., 2011)
- **Significant worries and confusion related to parent's cancer diagnosis, of parent dying and how the illness would impact not only the patient but also their family** (Morris et.al, 2018; Moller et.al, 2014; Karlson et.al., 2013; Visser et.al., 2004; Zahlis, 2001; Gazendam-Donofrio et.al., 2011)

Children of Parents with Cancer report:

- **Higher risk for internalizing-type problems** (Osborn, 2007; Jantzer et al, 2013)

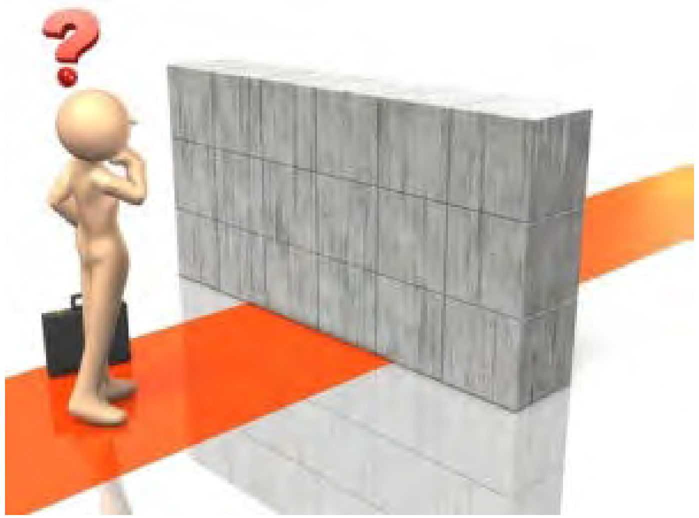
Child's adjustment worse:

- **Lower family cohesion correlated with higher risks of problems for children** (Watson et al., 2006)
- **Poor family communication correlated with externalizing behavior problems** (Watson et al., 2006)

Child's adjustment better:

- **Family communication and family functioning** (Osborn, 2007)
- **Children provided information about parent's illness associated with lower anxiety compared to those uninformed** (Huizinga et al, 2003; Rosenheim & Reicher, 1985)
- **Anxiety diminishes when a child is given opportunities to discuss fears** (Zahlis, 2001)

Barriers for Support of Families with Parental Cancer



Patient and Caretaker Beliefs

- **Children are generally resilient and they will eventually adapt to their circumstances on their own** (Kastenbaum, 1967; Pettle and Britten, 1995; Spinetta, 1974; Stambrook and Parker, 1987)
- **What they don't know, won't hurt them. Better to protect them from stress and worrying by not disclosing** (Kastenbaum, 1967; Pettle and Britten, 1995; Spinetta, 1974; Stambrook and Parker, 1987)
- **Particularly younger ones, do not really understand what is going on anyway. Therefore, it was best not to discuss the situation with them** (Kastenbaum, 1967; Pettle and Britten, 1995; Spinetta, 1974; Stambrook and Parker, 1987)
- **Despite children of cancer patients expressing the need and desire for parents' health information, parents report feeling unprepared and distressed by these communication challenges** (Walczak et.al, 2018; Kennedy and Lloyd-William, 2009).
- **For parents, most common reason for not communicating with child was to avoid questions, especially about death, most preferred health professional's assistance but not offered any** (Bradbuy et al., 2012)

Lack of Resources

- **Cancer patients with young children reported interest in receiving resources on communicating with their children and information regarding psychosocial services to support their children and parenting** (Sinclair etl.al, 2019; Ernst et. al, 2013)
- **Support and resources for parents with cancer to assist in these concerns and issues have been limited, particularly for patients with advanced cancer** (Semple and McCance, 2010; Turner et.al.,2007)
- **Significant others of cancer patients who co-parent children also have reported need for more information on how to support their children** (Forrest et.al., 2008)

Oncology Providers

Some potential barriers for oncologists and health professionals in addressing parenting concerns of their patients include (Rauch and Muriel, 2004):

- **limited time pressures**
- **not feeling equipped to provide recommendations or guidance**
- **due to their own emotional responses that may be elicited by talking with patients about their children**

Need for Child Focused Interventions

- **Need for age-appropriate information to assist children in making sense of events happening** (Worden, 1996; Christ et.al., 2005; Kennedy & Lloyd Williams, 2009)
- **Parent-child communication key element in supporting children** (Morris et al., 2016)
- **Systematic review of children's psychosocial needs and existing interventions** (Ellis et al., 2017)
  - Age-appropriate education about parent's cancer
  - Supported communication with parents and health professionals
  - Environments that normalize positive and negative feeling

Results of Needs Assessment Focus Groups of Patients and Partners

Formative research (n=25 patient-caregiver dyads)

Themes identified through qualitative interviews included:

- Deciding how to disclose the cancer diagnosis
- Sharing important information related to treatment and symptoms
- Concerns about discussing prognosis
- Difficulty accessing mental health services for the entire family
- Accessing support network to meet day-to-day family needs
- Support and communication between spouses

Whisenant, Jones, et.al., 2023

Support for children affected by cancer

Our licensed counselors can help patients with children of all ages by:

- Talking with children about your illness and what might happen.
- Addressing your concerns about how children may cope with your illness

Ask your Supportive Care team about our Ensuring Children Have Optimal Support (ECHOS) Program.

Clinical Observation: Most Frequently Encountered Questions from Parents/Guardians

1. Do I have to tell my child about my illness/diagnosis?

- They can discern when something is wrong in the family
- They will imagine worse than the cancer for the change in the family dynamics and parent/child interactions
- Without facts, children often assume responsibility for parental absence/inability to participate in play or family activities
- Children are better able to cope with reality than adults give them credit for
- Increase family communication and cohesion
- Facilitate trust of parents
- Better to be informed directly then to learn from another source

2. Do I have to use the word "cancer"?

- Children generalize sickness to self and other loved ones
- Better to be informed directly then to learn from another source
- Using the word cancer provides language to begin forming concept, differentiating and to ask questions
- Younger children use analogy for cancer
  - Legos, Grapes, Weeds in flower bed
- The 3 C's (Martha Aschenbrenner)
  - **C**ancer
  - Not **C**ontagious or not-**C**atchy
  - No one **C**aused it

Younger Children Cancer Education

3. What if my child asks me questions I can’t answer?

- Help parents anticipate common questions to be prepared with response
- Explore what made them think of that question.
- What have they heard.
- Validate the question.
- If you don’t know, be honest and offer to find out.
- Warn about internet

Anticipate responses based on developmental stage/age

- 5 years of age: minimal response
- 6-12 years of age: likely to ask about death

  *IMPORTANT: parent should respond with hopeful honesty (not my plan, my doctors are working hard to make my cancer go away, I want to live a long time)

  Often will become “caregiver” of parent
- Over 13: May exhibit little emotion (appropriate)

  May be concerned about how it affects their schedule

  Will rely on peers for help/support

4. Do I have to tell my child prognosis (progression, reoccurrence, or terminal status) ?

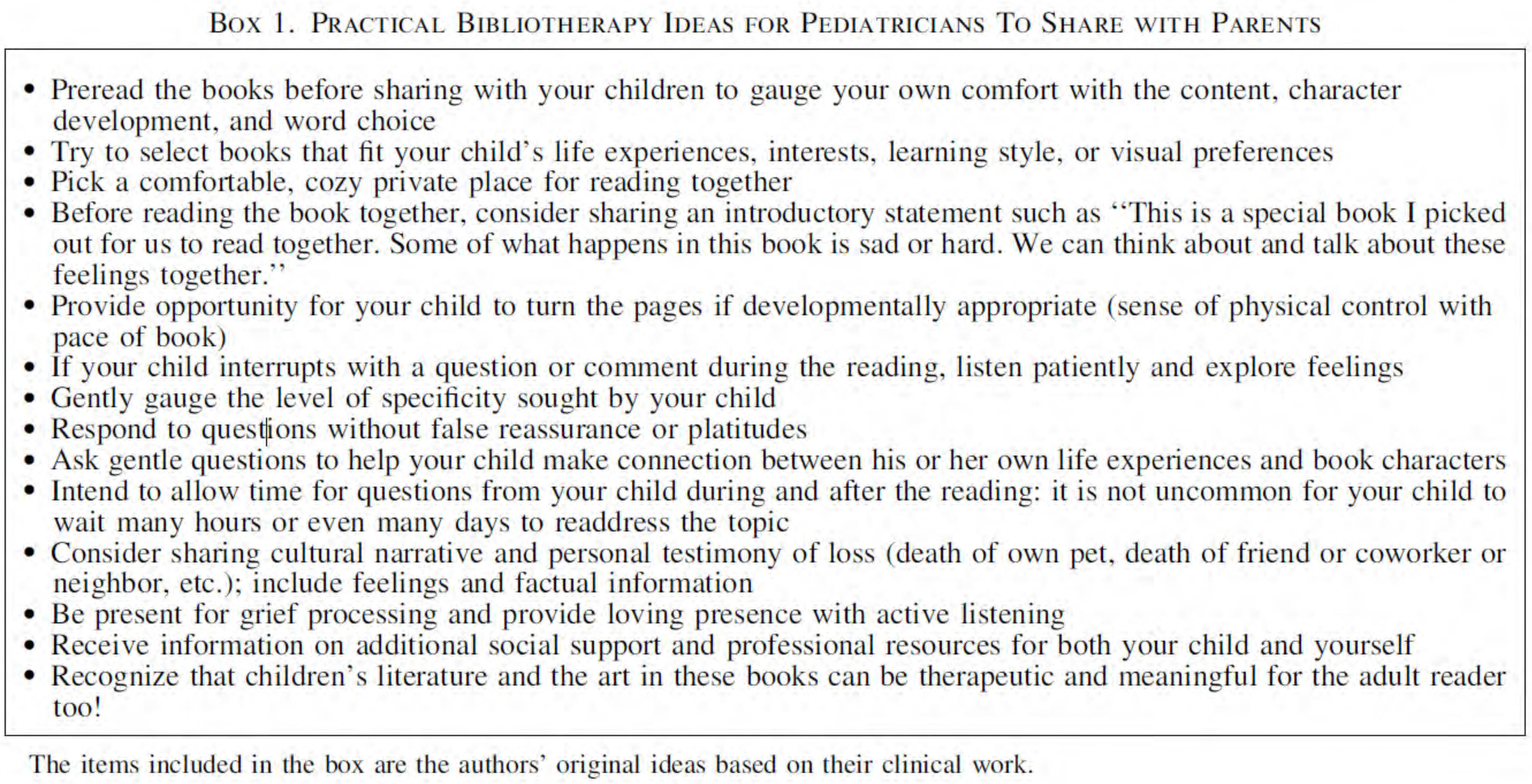
- To continue to preserve and facilitate trust, important to provide continued updates and especially at transition times when treatment plan or goals of care have changed
- Communicating progression or changes in goals of care provides natural opportunity to process and prepare
- Anticipate questions and developmentally typical responses

If approaching end of life:

- Death education: irreversibility (4 yrs), nonfunctionality (5 yrs), universality(9 yrs) (original study by Nagy, 1948)
- Explain physical changes
- Reassure parent is being cared for to minimize pain/ other symptoms
- Encourage time with parent *as they choose,* but allow for normal activities
- Ask how much information they want re: time of death, their presence, etc (no right or wrong answers to this)

Using Children’s Books to introduce Death

Arruda-Colli, Weaver and Wiener (2017). Communication about dying, death, and bereavement: A Systematic Review of Children’s Literature. *Journal of Palliative Medicine, 20, 548-559.*



Box 1. Practical Bibliotherapy Ideas for Pediatricians To Share with Parents

- Preread the books before sharing with your children to gauge your own comfort with the content, character development, and word choice
- Try to select books that fit your child’s life experiences, interests, learning style, or visual preferences
- Pick a comfortable, cozy private place for reading together
- Before reading the book together, consider sharing an introductory statement such as ‘‘This is a special book I picked out for us to read together. Some of what happens in this book is sad or hard. We can think about and talk about these feelings together.’’
- Provide opportunity for your child to turn the pages if developmentally appropriate (sense of physical control with pace of book)
- If your child interrupts with a question or comment during the reading, listen patiently and explore feelings
- Gently gauge the level of specificity sought by your child
- Respond to questions without false reassurance or platitudes
- Ask gentle questions to help your child make connection between his or her own life experiences and book characters
- Intend to allow time for questions from your child during and after the reading: it is not uncommon for your child to wait many hours or even many days to readdress the topic
- Consider sharing cultural narrative and personal testimony of loss (death of own pet, death of friend or coworker or neighbor, etc.); include feelings and factual information
- Be present for grief processing and provide loving presence with active listening
- Receive information on additional social support and professional resources for both your child and yourself
- Recognize that children’s literature and the art in these books can be therapeutic and meaningful for the adult reader too!

The items included in the box are the authors’ original ideas based on their clinical work.

Grief Support Books

5. When do I tell my child about dying?

- Teens need information as early as possible, weeks to months in advance
- 8-12 years of age: weeks to a month in advance
- 5-8 years of age: 1-2 weeks in advance
- < 5 years of age: 2-3 days in advance

6. Can I incorporate my spiritual beliefs when explaining death to my children?

- Incorporating family’s spiritual/religious beliefs can be source of comfort for children

- But be careful especially with children that do not understand death, ages <6, of using phrases such as “Mommy went to go be with God” or “Daddy went to heaven” for they may be taken literally

- Depending on where children are in their spiritual development, want to avoid pressure to pray or blame higher power or God

- May be beneficial to encourage a spiritual, supernatural connection with parent after death, e.g. guardian angel, continuing bond

7. Does my child need to be in counseling?

- Most children are resilient and if family provides communication and support, children typically adjust without any significant issues or insult to development
- If psychiatric history, lack of support, or significant impairment to functioning (academic, behavioral, emotional, social) then recommend further assessment and counseling
- Grief support groups facilitate normal grief process and provide peer group support
- If no identifiable concern and especially if resistant, can be more harmful than helpful to force counseling

Questions?
THANK YOU FOR ATTENDING