



KEEPING FAMILIES FIT FOR THE FUTURE:

*A STRATEGIC FRAMEWORK TO ADDRESS THE
COMPLEX NEEDS OF ADULT CANCER PATIENTS WITH
MINOR CHILDREN*

Brandy Ficek, M.D.
Medical Director, Quality of Life and Palliative Medicine
Cancer Treatment Centers of America®

13th Australian Palliative Care Conference 2015

Disclosure

I have no relevant financial relationships or conflicts of interest to disclose.



An Overview



Prevalence – United States

- Approximately 22.4% of cancer diagnoses in individuals aged 21 and 55 years
- 1.58 million cancer survivors have minor children living with them
 - 2.85 million children living with parent diagnosed with cancer
 - Estimates do not consider children who do not reside with the parent diagnosed with cancer or those impacted by the death of a parent

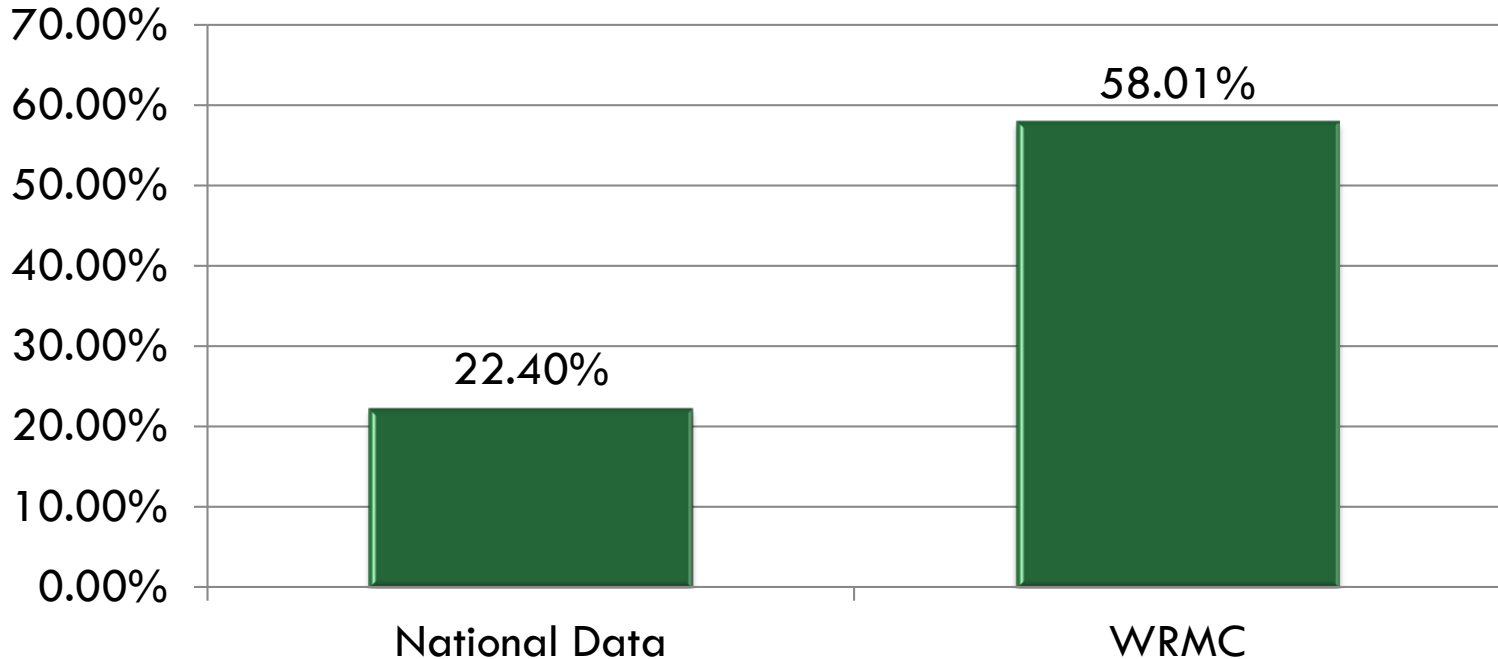


Prevalence – United States

- Grandparents' role in caregiving for minor children increasing
 - 5.8 million children under the age of 18 live in home where grandparent is head of household
 - Grandparents are primary caregivers for 2.6 million children
 - 1 million of these children have no parental involvement in care

Age Demographic

Percentage of Cancer Diagnoses in Patients 55 Years and Younger



Winning the fight against cancer, every day.®

Incidence in Australia

Source table 1: Incidence of cancer by age group, 2015

Age group (years)	Number of new cases per 100,000 people	
0-4	21.2	
5-9	10.3	
10-14	12.0	
15-19	21.7	
20-24	33.9	
25-29	64.1	
30-34	91.7	= 1292.7 new cases per 100,000 (8.9%)
35-39	148.5	
40-44	229.7	
45-49	368.9	
50-54	555.9	
55-59	819.6	
60-64	1,185.9	
65-69	1,715.3	
70-74	1,933.0	
75-79	2,198.9	
80-84	2,506.2	
85+	2,742.0	

Impact on Parents

- Lack of guidance in disclosure techniques
 - Instinct to protect
 - What words do I use?
- Physical limitations of parental role
 - Increased absences from events due to illness or treatment
 - Role reversals
- Nature of anticipatory grief
- Resultant higher levels of distress, poorer overall quality of life, and potential non-compliance than non-parent counterparts



Impact on Children

- Parental cancer evokes higher stress responses than if child experiences illness themselves
- Negative reactions include:
 - Mood changes
 - Academic changes
 - Somatic symptoms
 - Social/interpersonal changes

Highest Risk Groups

- Adolescents
 - Daughters are particular risk
 - Up to 35% with clinically significant symptoms
 - Withdrawal, somatic complaints, anxiety/depression, thought problems and attention problems
 - Knowledge of genetic traits such as +BRCA 1 or 2
- Physical changes are most distressing
- Pre-existing dysfunction in family
- Single parent families



Care Teams

- May have knowledge of childhood developmental stages but...
 - Often lack knowledge and skillset to apply knowledge to enhance coping in families facing cancer
 - “inhibited by their anxieties about saying or doing the wrong thing and causing lasting emotional damage”



Our Research

- Literature review (Pubmed, Medline via Ovid)
 - Limited by scarcity of high-quality research
 - Obtained theses, unpublished data
 - Gathered expert opinion
 - Utilized available research on pediatric illness, only as it relates to understanding of illness
- Developmental and social learning theories
- Consider both evidence-based solutions and feasibility/scalability



Four Guiding Principles



Acknowledge
Age-Specific
Emotional
Maturity



Utilize
Understanding
of Body
Processes as
Basis for
Disclosures



Empower
Parents to
Facilitate
Healthy Coping
at Home



Use Common
Narratives to
Legitimize
Experience

Four Guiding Principles

Age-Specific Emotional Maturity

- Young children (< 8 year old)
 - Egocentric, concrete-thinkers, belief in “magic”
 - Interpret bad events as punishment
 - Fear for their own safety and abandonment
 - Experience guilt for misperceived role in parents’ illness
 - Need:
 - Coping through play, reassurance that cancer is not their fault and that they will be safe and protected, patience when same question asked repeatedly



Age-Specific Emotional Maturity

- Middle Childhood (8 – 12 years)
 - Strong need of acceptance thus do not want to be viewed as “different”
 - Limited abstract thinking
 - Desire to be “brave”
 - Need :
 - Coping through play, opportunities to remain active with peers, decreased pressure to be brave, ways to address questions from others

Age-Specific Emotional Maturity

- Adolescents
 - Want to assert independence
 - Fluctuating ability to think abstractly
 - Unrealistic expectations may exist of adolescents
 - Incongruency of physical and emotional maturity
 - Regression during stress
 - Often feel anxiety about need to take on more responsibility for ill parent
 - Need:
 - Honest information, time with peers, acknowledgement of any changes in their roles



Understanding of Body Processes

- Utilize understanding of body processes as basis for disclosures
 - Children may understand concepts of body processes before they gain ability to understand other abstract concepts
 - Understanding of human body, life and death influenced by:
 - Education – nutrition and digestion
 - Experience – family members, animals

Understanding of Body Processes

- Will understand cancer better if they can first look at pictures and learn about (or review) how the human body works
- Simplify everything regardless of age
 - *Muscles allow us to move, lungs help us breathe, heart moves blood through our body...*
- Relate everything back to the body
 - *“The cancer cells aren’t allowing Mom’s lungs to do their job. This is why she can’t breathe as well.”*



Empower Parents

- Direct interventions with children must be complemented by parental training to empower parents with the necessary skills to support children
- Vast majority of circumstances that necessitate such support occur outside of the clinic and hospital environment



Empower Parents

- Parents often know their children the best.
 - *What kind of kid is Josh? What does he do in other situations when he is upset?*
- It is okay to not know the answer to every question.
- It's not always about the cancer.
- Presence is key.
- All emotions are okay, but what you do with the emotion is key.
 - Coping strategies may need to change frequently



Using common narratives

- Application of social learning theory
 - Learning through others' experiences
 - Modeling of effective coping by parents
- Can provide a sense of normalization and validation
 - Peer support
- Facilitates difficult conversations

Using common narratives

- *“I met with a boy the other day whose Mom had cancer. He was just a little bit older than you, but he told me that sometimes he gets mad when his Mom can’t come to his soccer games. Do you ever feel like that?”*
- *“I’m really sad today. Sometimes I feel better when I go for a walk, will you go with me?”*
- *A lot of parents I work with worry about how to talk about death with their children. One of the ways that other parents have handled this is to...”*



Application of Concepts

- 1:1 interventions
 - With parents
 - With children by age-group
- Retreats
- Training of nursing and pastoral care staff
- Age-specific resource books and handouts
- Use for all new program building

Application of Concepts

- Addressing physical changes – Hair Loss
 - 1) Acknowledge Age-Specific Emotional Maturity
 - Nowhere Hair, My Mom Has Cancer, age-specific handouts; dolls, playdoh, brightly colored wigs and headwraps for families, choices of styles
 - 2) Use Body Processes as Basis for Disclosures
 - Explain hair loss as process of medication
 - Hair can be replaced
 - 3) Empower Parents
 - Parents to prep children and give choices
 - 4) Common Narratives
 - Pictures of families, famous bald people



Our Results

- Post-training evaluation by 50 nurses:
 - Significant improvement in:
 - Belief that RNs have important role in providing support for patients with minor children
 - Adequate knowledge to help address fears of children visiting inpatient unit
 - Self-perceived competence in working with families
 - 92% found framework extremely helpful, 8% helpful

Our Results

- Over the first year of utilizing framework:
 - Over 100 families helped
 - Training expanded to all nursing staff and pastoral care staff
- Second year:
 - Expand to 4 additional sites
 - Expect to help over 1000 families
 - Part of orientation for all new stakeholders

Our Results



Questions?