

EARLY WARNING SIGNS OF PSYCHOSOCIAL RISK IN CHILDREN WITH CANCER AND THEIR FAMILIES

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Presentation Outline

- Overview
- **Research** on Psychosocial Outcomes of Pediatric Cancer
- **Risk Factors** for Psychosocial Adjustment
- **Definitions:** Psychosocial distress, Distress in Children, Psychosocial Risk, **Psychosocial Screening**, Psychosocial Assessment.
- Patient-Centered Care vs **Child-Family Centered Care.**
- **Barriers** to Psychosocial Screening, assessment and Care.
- Psychosocial Screening **tools.**
- **Guidelines and Standards** for Psychosocial Services in **Pediatric Oncology**
- **Recommended Psychosocial Screening tools** and follow-up Plan

Overview

- A diagnosis of childhood cancer is a life changing event for every family member, not just the patient.
- For parents, the existential threat of cancer on their child's life is devastating;
- **Parents** come to the fundamental and sudden realization they can no longer fully protect their child's life.
- For the **child with cancer**, painful and fearful experiences, physical changes, and social and family life changes could have a severe impact on their overall wellbeing.
- For the other children in the family, **the siblings**, life too will change and will have an impact on their every day life and how they see themselves in the family.

Overview (cont.)

- Are all children and parents able to face these new medical challenges and changes in their lives with flying colours?
- How the affected child, parents, and siblings manage these new experiences varies greatly, depending on a variety of **risk** and **resilience factors** within themselves and their ecological social-family environment.

Research on Psychosocial Effects of Pediatric Cancer

- **Early stages of treatment.** Highly stressful for the child with cancer and the entire family (Patenaude & Kupst, 2005; Sawyer et al, 2000; Vannatta, Salley, & Gerhardt, 2009).
- **Sick child** may become highly anxious and distressed during hospitalizations and medical procedures, as demonstrated by their acting out, irritability or becoming socially withdrawn (Barrera et al, 2003; Kazak et al, 2007; Okado et al, 2014).
- **Parents** can become overwhelmed and distressed, manifested by mood changes, increased symptoms of anxiety and depression, difficulties sleeping, etc. (Barrera et al, 2004; Boman et al, 2003; Manne et al, 2000; Rodriguez et al, 2012 ; Sloper, 2000; Vrijmoet et al, 2008).
- **Siblings** are frequently separated from parents and the ill child, experience disruptions in their daily lives, worry about the ill child, and become highly distressed (Alderfer & Hodges, 2010; Kaplan et al, 2013; Vermeas et al, 2012).

Research on Psychosocial Effects of Pediatric Cancer (cont.)

- Most children and parents adjust well over time;
- **A significant subgroup** of children with cancer, parents and siblings develop serious psychosocial difficulties
(Boman et al, 2003; Kazak et al, 2002, 2007, 2012; Patenaude & Kupst, 2005; Sawyer et al, 2000; Vannatta, Salley, & Gerhardt, 2009; Wijnberg-Williams et al, 2006; Zeltzer et al, 2009).
- Left untreated, these difficulties may become a serious mental health illness that may interfere with cancer treatment and re-integration in the community after treatment is completed.

Risk Factors for Psychosocial distress and Poor Quality of Life in Pediatric Cancer Patients and Families

- Low household income
- Unemployment
- Limited social support
- Major medical (physical, mental) condition in the family
- Treatment with brain radiation (and HD methotrexate)
- Gender (female survivor)
- Age (for siblings: being younger than survivors; for affected child under 6 years: externalizing behaviour; for affected teen: internalizing behaviour)
- Child behavior (for parent),
- Parent's adjustment (for child)

(Barrera et al, 2003,2004, 2015; Buckbinder et al, 2011; Kazak et al, 2006, 2012; Wijnberg-Williams et al, 2006; Zeltzer et al, 2009)

Psychosocial Distress

VS

Psychosocial Risk

Psychosocial Distress

- The National Comprehensive Cancer Network (NCCN) defines **distress** as:

*a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and spiritual nature that **may interfere with the ability to cope** with cancer, its physical symptoms and its treatment (NCCN, Distress Management Guidelines Panel in Oncology, 2002);*

- NCCN recommended: “*Distress should be **recognized, documented, and treated promptly at all stages of disease and in all settings, and all patients should be screened***”
- **Psychosocial distress** in the affected child, parents/ caregivers, siblings and every family member is the norm, rather than the exception.

Psychosocial Distress

- **Distress** is conceptualized along a continuum:

Normal feelings of:

- wellbeing
- happiness
- sadness
- vulnerability
- Fear, encountering a stressful, adverse, traumatic situation/ event

Responses that can become disabling:

- anxiety
- panic
- depression
- social isolation



Psychosocial Distress in Children

- **In children, distress** can be manifested as:
 - lack of energy
 - pain, fatigue, nausea
 - lack of appetite
 - sadness, irritability
 - inability to focus or concentrate
 - nervousness
 - worry
 - clingy
 - acting out

Psychosocial Risk in Pediatric Cancer

- Defined as **vulnerability** or **likelihood** to alter typical behavior or functioning and manifesting difficulties in functioning or coping **when encountering a stressful, disruptive or traumatic event such as cancer**

Considers:

- Present and past experiences, personal and external resources of the child and family
- **Risk** (*e.g., previous medical, chronic or mental health condition; financial difficulties*) and **protective factors** (*e.g., high functioning, strong social/family support*) in the child and family
- Based on risk/prevention model

(Kazak et al, 2006)

Pediatric Psychosocial Preventive Health Model

Clinical/Treatment

- Persistent and/or escalating distress
- High risk factors



Consult behavioral health specialist

Targeted

- Acute distress
- Risk factors present



Provide intervention and services specific to symptoms. Monitor distress.

Universal

- Children and families are distressed but resilient



Provide general support – help family help themselves
Provide information and support. Screen for indicators of higher risk

Screening for Psychological Distress and Psychosocial Risk

- **Medical screening:** application of *a screening tool* to individuals in the population to detect a medical condition that can be alleviated with intervention (Meijer et al, 2013)
- **Screening for distress or psychosocial risk:**
 - The **first necessary step** in improving clinical psychosocial care
 - Aims to identify early warnings of distress or psychosocial risk and to link screening to **evidence-based psychosocial care, services or interventions** (Kazak et al, 2011)
- **Challenges for Psychosocial Screening**
 - Less well defined
 - Requires:
 - a clear goal of **what is being screened for**
 - a **valid**, psychometrically strong, distress or psychosocial **screening tool** with predefined cut-offs, to identify individuals or families for services or interventions to reduce distress or psychosocial risk (Kazak, et al, 2011)
 - a **strong mandate, and acceptance by all stakeholders** (Holland, 2010; Kazak et al, 2011)

Challenges Screening for Distress in the Individual Child with Cancer

- **Majority of children are diagnosed before 5 years of age**, (*developmental limitations to reliably self-report emotional experiences and psychosocial wellbeing*- Altekruise et al, 2010; Varni et al, 2007- *even when they may be able to report reliably on procedural pain* -Cohen et al, 2008).
- **We cannot consider child's distress in isolation**, (*well established evidence indicating that the psychosocial wellbeing of children is closely linked to the wellbeing of their caregivers*, e.g., Barrera et al, 2003, 2004; Caes et al., 2014; Kazak et al., 2011; Okado et al, 2014).

Patient-Centered Care vs Child-Family Centered Psychosocial Care

- In adult oncology, **patient-centered** care is the model of care
- In pediatrics, a **child-family centered model** of psychosocial care has been advocated in the field, based on the strong evidence of the psychosocial impact of childhood cancer on the affected child, parents, and siblings
- The C-F centered model acknowledges **the reciprocal influences** among family members on their psychosocial functioning, particularly when encountering a stressful event such as pediatric cancer

(Barrera et al, 2003; Barrera et al, 2004; Enskar et al, 2014; Kazak et al, 2007; Okado et al, 2014; Patenaude & Kupst, 2005; Rodriguez et al, 2012; Wiener & Pao, et al, 2012)

Barriers to Psychosocial Screening and Services

Surveys of pediatric psychosocial services in centers in the UK (Mitchell et al, 2005) and COG member institutions (Selove et al, 2011).

Lack of standardization

Services lack standardization and most sites do not use validated assessment tools or evidence-based psychosocial interventions.

Limited Use of Validated Tools

*Services appeared to be offered without using validated tools for systematically assessing patients and family needs **in the first 30 days** after diagnosis (p4 , Selove, 2011).*

Family Difficulties

63% reported family time constraints

50% reported family transportation difficulties and distance to the center prevented receiving psychosocial interventions

Barriers to Psychosocial Services and Screening (cont.)

Inadequate Funding/Resources:

- 70% reported inadequate funding for psychosocial staff (Selove, et al, 2011)
- Insufficient consultation time to screen for psychosocial problems (Surveyed 537 physicians in Sweden; Fagerlind et al, 2013)
- Current psychosocial resources are limited to conduct psychosocial screening (interviewed 22 physicians, social workers, and nurses; Barrera et al, 2015, CCSRI, Phase 1)
- Reimbursement/funding challenges (Patenaude et al, 2015, IPOS)

Barriers to Psychosocial Services and Screening (cont.)

Institutional Policy/Standards Supporting Psychosocial Care

- HCPs *perceived lack of psychosocial standards and policy to support psychosocial screening as part of standard care* (Barrera, 2015, CCSRI, Phase 1);
- *Concerns regarding lack of resources to follow-up after psychosocial screening* (Barrera, 2015, CCSRI, Phase 1; Fagerlind et al, 2013);
- *Key stakeholders must recognize the importance and complexity of psychosocial care* (Patenaude et al, 2015, IPOS).

Barriers to Psychosocial Services and Screening (cont.)

Available instruments to screen or assess:

- *Lack of instruments to evaluate patients' psychosocial health in clinical practice* (Fagerlind et al, 2013);
- *Limited psychosocial assessment measures to screen in pediatric oncology* (Barrera et al, 2015 CCSRI, Phase 1; Fueemmeer et a., 2002; Liptak et al, 2012; Mitchell et al, 2005; Selove et al, 2011);

HCPs' Perceptions about families:

- *63% reported family time constraints; 50 reported family transportation difficulties* (Selove, et al, 2011);
- *Parental honesty in responding to psychosocial surveys or screening tools, (e.g., Afraid to be judged and stigmatized)* (Barrera et al, 2015 CCSRI, Phase 1; Patenaude et al, 2015, IPOS);
- *Cultural beliefs about the health system and family* (Barrera et al, 2015 CCSRI, Phase 1);
- *Parental English as a second language, education, and reading level* (Barrera et al, 2015 CCSRI, Phase 1);

Barriers to Psychosocial Services and Screening (cont.)

HCPs' Personal Attitudes and Beliefs

- *Less psychosocially oriented oncologists perceived more barriers affecting psychosocial clinical practice (Fagerlind et al, 2013);*
- *Some HCPs expressed concerns about sharing psychosocial information with the rest of the health care team (Barrera et al, 2015, CCSRI, Phase 1);*
- *Some HCPs did not believe standardized tools were needed, as psychosocial staff were already assessing families (Barrera et al, 2015, CCSRI, Phase 1).*

Distress Thermometer (DT)

- As in adults, DT for children is a single item self-rating, a VAS presented as a thermometer, in response to the question: *how distressed have you been feeling in the last week?*
- **For children, DT** has been adapted using faces for children 2-7 yrs. The question is:

How worried, sad or fearful have you been in the last week?

- 2-4 year olds: 3 faces,
5 to 7 year olds: 10 faces

The scale is 1-10;

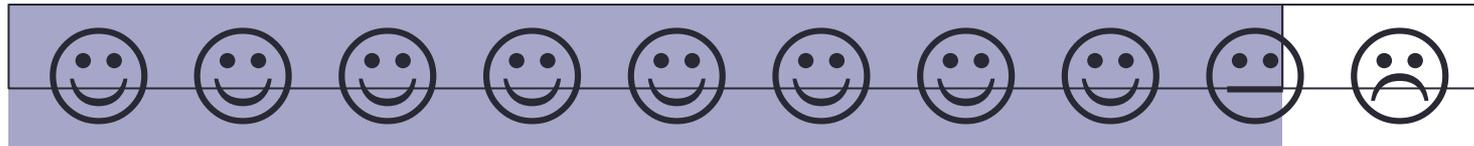
0-3 = no distress;

4-7 moderate distress;

8-10 high or extreme distress.

- DT is commonly used along with a problem checklist (emotional, physical, practical, spiritual 7 family/social problems)

Distress Thermometer



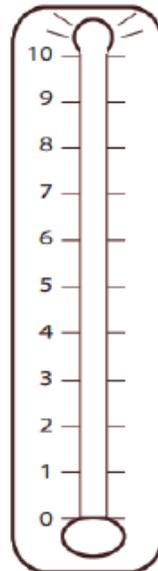
PEDIATRIC DISTRESS THERMOMETER

Adapted from Patel SK, M.W., Turk A, Dekel N, Kinjo C, Sato JK., *Distress screening, rater agreement, and services in pediatric oncology*. *Psycho-Oncol* 2011. 20: p. 1324-1333.

"Distress" can be worry, anxiety, sadness or fear

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

10 = High Distress



5 = Moderate Distress

0 = No distress

Version 1 – September 8, 2015

Emotional Problems

- Worry/Anxiety
- Nervousness (e.g. butterflies in your tummy)
- Sadness/Depression
- Loneliness/Feeling Isolated
- Fear
- Boredom
- Passivity (e.g. sitting around for a very long time, not feeling like moving)
- Irritability (e.g. annoyed)
- Not Following Directions From Adults
- Disagreement With Medical Staff (e.g. doctors, nurses)
- Anger
- Other Problems: _____

Physical Problems

- Pain
- Nausea (feeling sick to your stomach)
- Fatigue (feeling tired)
- Falling Asleep
- Sleep Through The Night
- Bathing/Dressing
- Eating
- Digestion (e.g. upset stomach after eating)
- Fevers (e.g. having a high temperature when sick)
- Skin Dry/Itchy
- Nose Dry/Congested (e.g. "stuffy nose")
- Tingling Hands/Feet (e.g. hands "falling asleep")
- Getting Around (moving around)
- Other Problems: _____

Practical Problems

- School
- Work
- Household Chores
- Personal Hygiene (e.g. brushing teeth, taking a bath/shower)
- Not taking/Missing Medications
- Other problems: _____

Spiritual Problems

- Spiritual Questions
- Difficulties Praying
- Feeling Distanced from God
- Loss of Faith
- Other Problems: _____

Family/Social Problems

- Dealing (getting along) with Parents
- Dealing (getting along) with Siblings
- Family Issues (problems)
- Dealing with Old Friends
- Dealing with New Friends
- Other Problems: _____

Pediatric Distress Thermometer: Validity and Reliability

- **Distress Thermometer (DT)** to assess children's (Patel et al, 2011; Zadeh et al. 2015) and parents' distress (Haverman et al., 2013)

Pediatric DT was validated with measures of depression and quality of life (Patel et al., 2011; Zadek et al, 2015):

- **Modest validity** compared to CDI or PedsQL emotional (or BSI-18 for parents)
- **Modest inter-rater reliability** (some discrepancy of ratings by the child, parent, and staff)
- **Inter-rater reliability** increased with age (Zadek et al, 2015)
- The **cut-off of 4** yields high sensitivity for clinical cases.
- **DT could be useful during pediatrics clinic visits.**

Psychosocial Assessment Tool (PAT)

- Based on a **social ecological/contextual framework** and evidence of psychosocial effects of pediatric cancer in the affected child AND the family;
- Screens for: **contextual risk and resilience factors** (family support, family size, financial burden) and existent psychosocial problems (Y/N) in **child, sibling** (moods, worries, fears, attention, learning, risk behaviours), and **caregiver** (worry, fear, sad, attention, MH, alcohol);
- Its underlying conceptual model is the **Pediatric Psychosocial Preventive Health Model** of risk(PPPHM);
- Using PAT, families can fall within the following levels of risk, based on PPPHM :
 - **Universal** (low risk, the majority of families)
 - **Targeted** (moderate risk, about a quarter of families)
 - **Clinical** (high risk, a small group of families) (Kazak et al, 2001; Pai et al, 2008)

Pediatric Psychosocial Screening Tool

Components

- **Practical resources**
- **Family problems**
- **Family Social Support**
- **Caregiver Stress Reactions**
- **Family beliefs**
- **Child problems**
- **Sibling problems**
- **Total Score**

2. RELATIONSHIP STATUS OF PARENT/CAREGIVER: (PLEASE ✓ ONE)

Single Married/Partnered Separated/Divorced Widowed Other (please describe):

3. IS ANYONE IN THE HOUSEHOLD PREGNANT OR PLANNING TO ADOPT? No Yes

4. WHO CAN YOU ASK TO HELP WITH: (PLEASE CHECK ALL BOXES THAT APPLY)

	My Spouse/partner	Child's main/other caregiver	Child's grandparents	Other family members	Friends	People at work	Church/Spiritual Community	Other (list)	No one
Childcare/Parenting									
Emotional Support									
Money/Financial Support									
Information									
Help with everyday tasks (for example: meals)									

5. HOW WILL YOU GET TO THE HOSPITAL FOR APPOINTMENTS?: (PLEASE ✓ ALL BOXES THAT APPLY)

Own car Rides from others Cancer Society/Volunteer drivers
 Public (bus, subway, train) Not sure/Don't know

6. WHAT TYPE OF HEALTH INSURANCE DOES THE CHILD HAVE: (PLEASE ✓ ALL BOXES THAT APPLY)

OHIP Interim Federal Health Drug Coverage Yes No
 Other (please describe) If yes, what %? _____%

7. IS YOUR FAMILY CURRENTLY EXPERIENCING ANY MONEY PROBLEMS? (PLEASE ✓ ONE)

No problems

Some problems

Many problems

It's hard for the family to meet its needs

†

†

†

†

8. IN WHAT AREAS ARE THERE MONEY PROBLEMS? (PLEASE CHECK ALL BOXES THAT APPLY)

None Phone/heat/light bills Paying rent/mortgage Buying food Car costs (upkeep/gas/insurance) Medical bills

9. DOES YOUR CHILD KNOW S/HE HAS CANCER?

Yes him/her

No, too young to know

No, decided not to tell

10. CHILD'S DAY CARE/SCHOOLING STATUS: (CHECK ALL BOXES THAT APPLY)				† Too young for school → SKIP to #11	
<input type="checkbox"/> Nursery School/Preschool	<input type="checkbox"/> K-12; Grade? —	<input type="checkbox"/> Home Schooling	<input type="checkbox"/> Gifted program (full-time)	<input type="checkbox"/> Gifted program (part-time)	
<input type="checkbox"/> Special education (Full Time)	<input type="checkbox"/> Dropped out	<input type="checkbox"/> Completed formal education			
<input type="checkbox"/> Special education (Part Time)	<input type="checkbox"/> Not attending school by parent's choice				
11. IN GENERAL DOES HE OR SHE: (PLEASE ✓ ONE BOX FOR EACH QUESTION)				12. IS THIS A PROBLEM FOR OTHER CHILDREN AT HOME?	
	No	Sometimes	Yes/Getting help	<input type="checkbox"/> No other children	
a. Seem moody/change moods a lot?				No	Yes
a. Acts younger than his/her age?					
a. Gets upset about going to the doctor/dentist?					
a. Seem overly active or can't stand still?					
a. Have attention difficulties/ADHD?					
a. Cry easily or become upset easily?					
a. Get distracted easily?					
a. Worry a lot?					
a. Have learning problems or problems at school?					
a. Seem sad or keeps to herself/himself?					
a. Use drugs, alcohol or other substances?					
a. Have developmental problems compared to kids the same age?					
a. Act shy or cling to you/other familiar adults?					
a. Have problems making or keeping friends?					
a. Have a pre-existing medical condition? (Describe)					
a. Been a victim of crime or violence, inside or outside the home?					
a. Another psychological concern? (Describe)					

13. ABOUT THE ADULTS CARING FOR THE CHILD (PLEASE ✓ ONE BOX FOR EACH QUESTION):

	No	Yes
a. Has anyone had a lot of worry, fear, or anxiety at times?		
a. Have drugs or alcohol caused problems for anyone in the family?		
a. Has anyone been sad or depressed at times?		
a. Does anyone have problems paying attention/staying focused/concentrating for periods of time?		
a. Have there been relationship problems, fights, or talk about breaking up or divorce?		
a. Has anyone been in jail/is anyone now in jail?		
a. Has anyone been told that he/she drinks too much alcohol?		
a. Have there been any legal problems with child custody or with who should raise your child?		
a. Is anyone really sick or have a serious medical problem? (List)		
a. Does anyone have other mental health problems?(List)		
a. Has anyone in the family died in the past year?		

14. SINCE DIAGNOSIS ... (PLEASE CIRCLE ONE FOR EACH ITEM BELOW)

	Not at all	Sometimes	Often	Very Much
a. Have you had bad dreams or nightmares about your child being ill?	0	1	2	3
a. Have you become jumpy since your child was diagnosed with cancer?	0	1	2	3
a. When you are reminded of your child being ill, do you sweat or tremble, or does your heart beat fast?	0	1	2	3

15. AS A CAREGIVER FOR THE CHILD, HOW MUCH DO YOU BELIEVE ... (PLEASE ✓ ONE BOX FOR EACH STATEMENT BELOW)

	Not true for me	A little true for me	Mostly true for me	Very true
a. The doctors and nurses will know how to help				
a. My child will be in a lot of pain				
a. Our family will be closer because of this				
a. Our marriage or family will fall apart				
a. This is a disaster				
a. We can make good treatment decisions				
a. People will pull away from us				
a. We're going to beat this				
a. Cancer is a death sentence				
a. Everything happens for a reason				

Psychosocial Risk of Families of Children Newly Diagnosed with Cancer: External, Cross Country Validity

Author/Country	Universal(%) (low risk)	Targeted(%) (medium risk)	Clinical(%) (high risk)
Barrera et al.(2013) (Canada)	60	31	9
McCarthy et al. (2009) (Australia)	69	23	9
Pai et al. (2008) (USA)	61	32	7

Utility of Psychosocial Assessment Tool

Kazak et al (2011, Psych-Onc)

- *Use of psychosocial screening, PAT, and type of psychosocial services provided to families;*
- *Historical comparison: families who did not complete the PAT*

Outcomes: SWs and CLS reports (chart review)

Results: Families that completed PAT received more services than families that did not complete PAT.

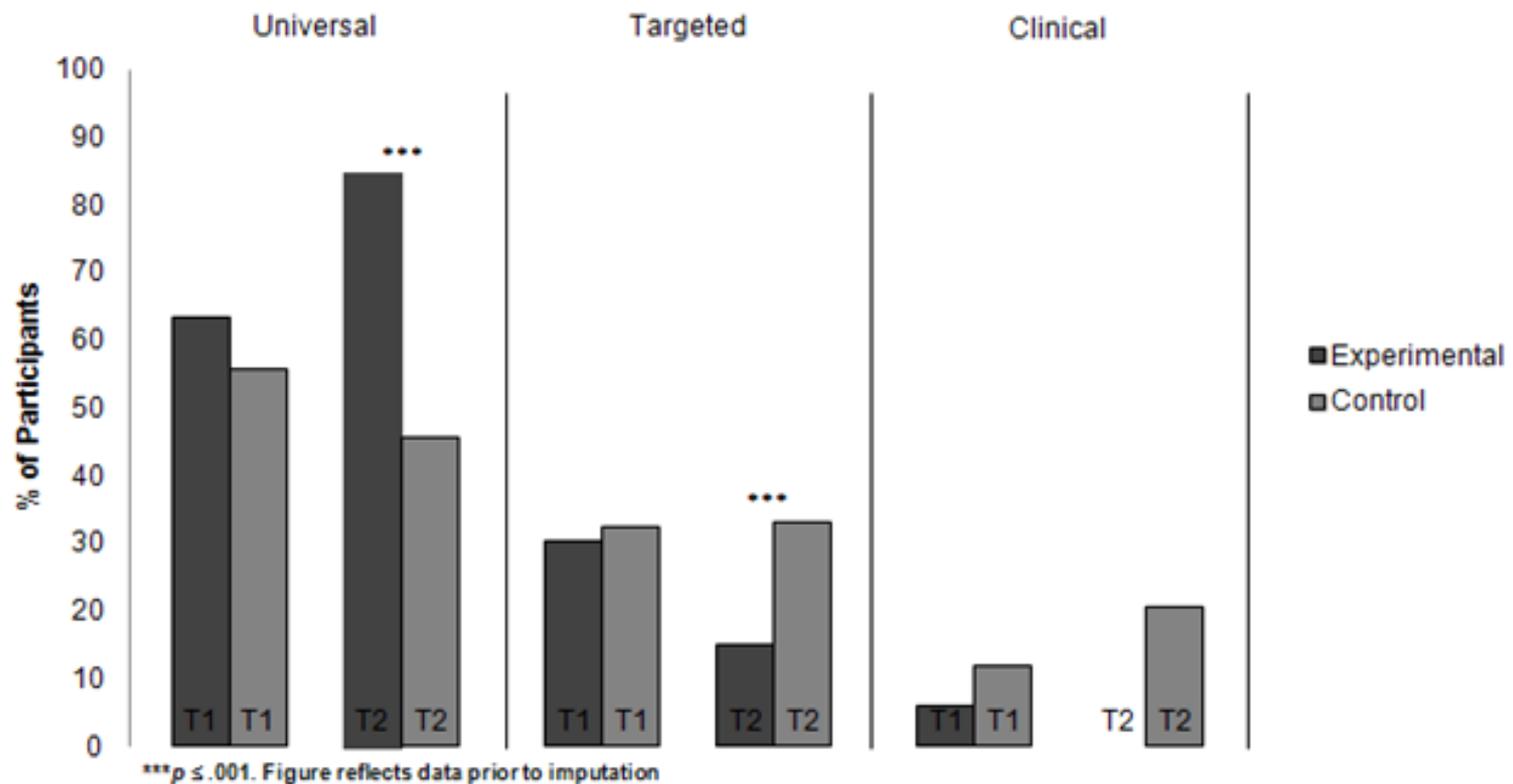
Families in the clinical and targeted risk categories received more intense services than those in the universal risk category.

Utility of Psychosocial Assessment Tool (cont'd)

- Barrera et al (2013, Psycho-Onc)
- **RCT** and repeated measures (6 months apart).
- **Outcomes:** QOL and PAT risk levels. PAT and PedsQL (about pt.) were completed by parents
- **EG:** HC -team **received PAT's summary** describing the family risk factors and level of risk;
- **CG:** HC-team for **did not receive the PAT's summary.**
- **Results:** Compared to CG, EG reduced clinical and targeted risk frequency and improved QOL pain related 6 months later
- **Recommended for early and follow-up psychosocial screening at critical periods of cancer trajectory**

(funded by POGO Research Unit)

Risk Categories at Baseline and Follow-up for the Experimental and Control Groups



Psychosocial Care Checklist (PCCL)

- PCCL, completed by **HCPs** identifies psychosocial issues for a child with cancer, siblings and caregivers, and
- Assesses HCPs' knowledge of psychosocial issues in the family.
- It consists of 20 items, (7 ill child, 7 sibling, 6 family).
- **Moderate to strong inter-rater reliability** (oncologist-nurse).
- **Strong test-retest** reliability and internal consistency;
- **Strong validity** compared to PAT results.

- **Recommended for team's monitoring of psychosocial functioning of patient and family at regular intervals**

(Barrera et al, 2015, Cancer Nurs)

Psychosocial Care Checklist (PCCL)

Instructions: Please complete the following checklist referring to the definitions provided. (See *Psychosocial Care Checklist Descriptors* attached).

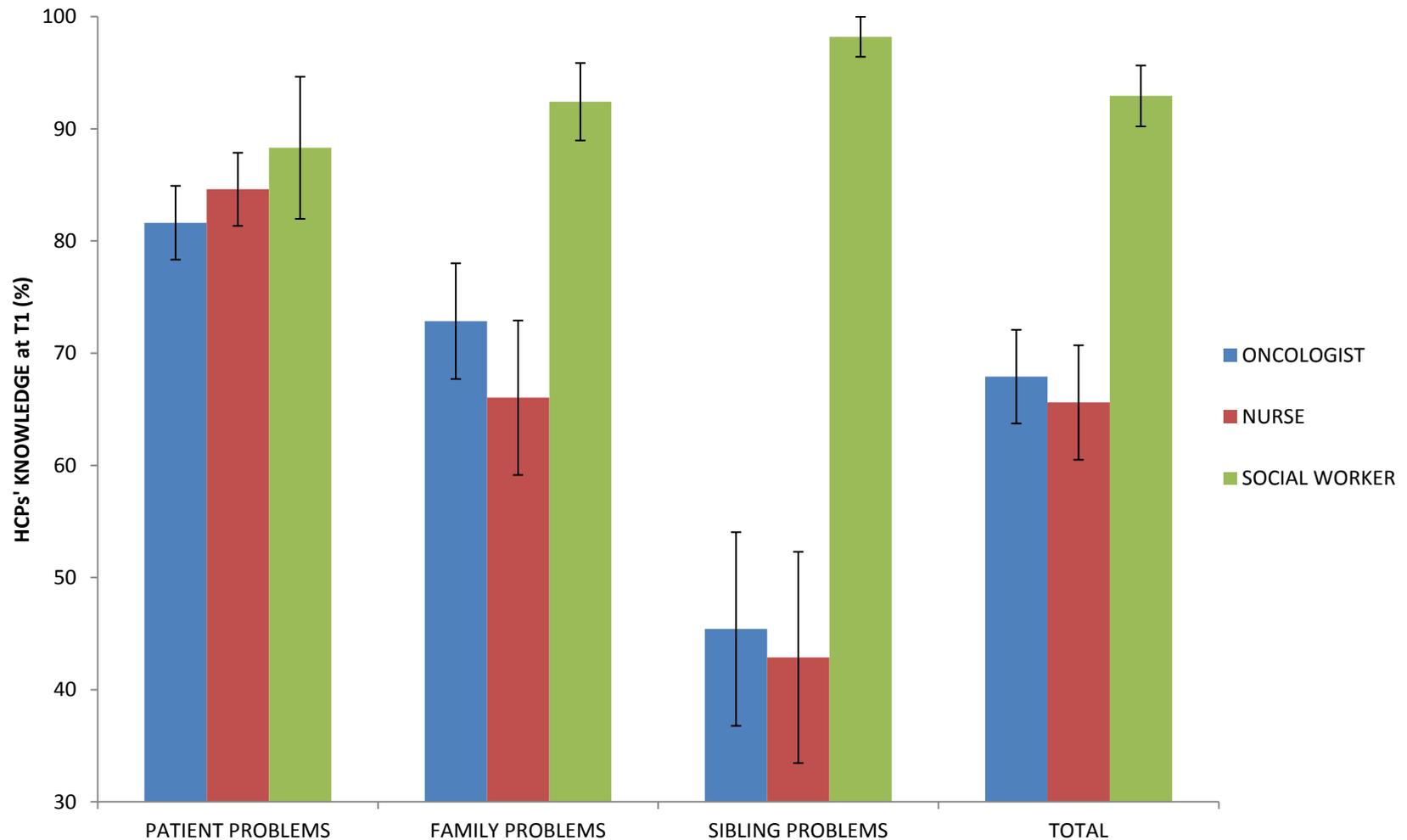
An “issue” is something that is atypical of what you would see under similar circumstances.

ISSUE(S)	ISSUE?			REFERRAL MADE?		REFERRED TO (PLEASE SPECIFY DISCIPLINE) DATE	ADDITIONAL COMMENTS
	YES	NO	UNKNOWN (U)	YES	NO		
PATIENT MOODY OR WITHDRAWN	Y	N	U	Y	N		
PATIENT ACTING OUT-AGGRESSIVE	Y	N	U	Y	N		
PATIENT ANXIOUS	Y	N	U	Y	N		
PATIENT SCHOOL WORK	Y	N	U	Y	N		
PATIENT SOCIAL ISSUES	Y	N	U	Y	N		
SIBLING MOODY OR WITHDRAWN	Y	N	U	Y	N		
SIBLING ACTING OUT-AGGRESSIVE	Y	N	U	Y	N		
SIBLING ANXIOUS	Y	N	U	Y	N		
SIBLING SCHOOL WORK	Y	N	U	Y	N		
SIBLING SOCIAL ISSUES	Y	N	U	Y	N		
FAMILY FINANCIAL ISSUES	Y	N	U	Y	N		
FAMILY LIMITED SOCIAL SUPPORT	Y	N	U	Y	N		
FAMILY MEDICAL ISSUES	Y	N	U	Y	N		
PARENTAL DISTRESS	Y	N	U	Y	N		
OTHER (PLEASE SPECIFY)	Y	N	U	Y	N		

Psychosocial Care Checklist Descriptors

ISSUE AREA	DEFINITION
PATIENT/SIBLING MOODY OR WITHDRAWN	Patient/sibling displays swings in emotion, both positive and negative, and/or is spending more time alone than other kids in the same age group.
PATIENT/SIBLING ACTING OUT - AGGRESSIVE	Patient/sibling is: having temper tantrums, refusing to comply with procedures or directions, and/or using or threatening to use physical actions, such as hitting, when things don't go his/her way.
PATIENT/SIBLING ANXIOUS	Patient/sibling is: irritable, experiencing sleep issues, fidgety, clingy, and/or having severe emotional reactions related to treatment procedures, etc.
PATIENT/SIBLING SCHOOL WORK	Patient/sibling is having difficulty, concentrating and/or completing school work.
PATIENT/SIBLING SOCIAL ISSUES	When patient/sibling is with other kids, he/she has difficulty reading social cues and/or playing with them. He/she may be bullied/teased.
FAMILY FINANCIAL ISSUES	Family is experiencing difficulties meeting their basic needs, such as: paying rent/mortgage, utilities, etc. Family is: unable to purchase uncovered costs associated with their child's illness (e.g., food supplementation; parking fees), recently unemployed, and/or may be new immigrants with limited resources, etc.
FAMILY LIMITED SOCIAL SUPPORT	Nuclear family has few family or friends who help during difficult times, and/or is experiencing issues within their social network/community (e.g., conflict with extended family, unsupportive community).
FAMILY MEDICAL ISSUES	One or more family members (aside from identified child with cancer) has medical issues that require considerable attention on a daily basis, and/or which may be impacted negatively by the child's cancer diagnosis (e.g., parent with lupus, heart condition, depression, anxiety).
PARENTAL DISTRESS	Parent(s) is experiencing significant emotional distress that impairs his/her own ability to function as they did previously (e.g., parent is: crying easily, not caring well for his/herself, not sleeping, experiencing difficulty coping with patient treatment demands and/or daily activities).

Family Psychosocial Knowledge by Discipline in Pediatric Oncology





Other Psychological Screening Efforts in Pediatric Cancer

Neurobehavioural and Psychosocial Screening (Pejnovic et al, 2012)

- N = 59 newly diagnosed with cancer
- Received CNS- direct therapy (Rads or Intrathecal chemo)
- Screened for: developmental, cognitive, academic, behavioural, and psychosocial (PAT) functioning.
- Feasibility assessed by criteria of brevity, simplicity, relevance, acceptability, and value.
- **Results:** Assessments were completed within 1 hr. in 87% of participants, 5.79 wks. from Dx.
- Compared to standard record documentation, screening provided sig. additional info on developmental, psychosocial, and neurobehavioural status of patients at diagnosis.

Other Psychological Screening Efforts in Pediatric Cancer (cont.)

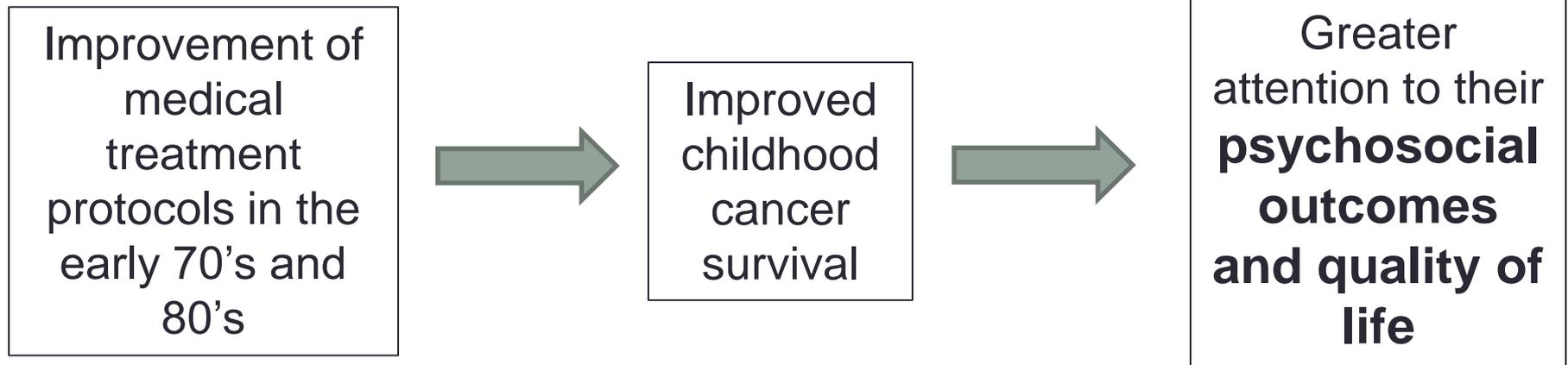
Pre-morbid developmental vulnerabilities (DV) (Janzen et al, 2015)

- Assessed pre-existing DV in newly diagnosed children with leukemia.
- N = 115, 2-18 years. 23% had prior DV (delayed early milestones, DS, autism spectrum, ADHD, learning disability, or neurological condition).
- 23% positive for prior DV. Important to guide treatment and interventions.

Baseline neuropsychological profile of children with brain tumors (BT) compared to other cancers (Margelisch et al, 2015).

- N = 20 BT, 27 other cancers without CNS involvement aged 6-16.9 yrs.
- BT performed worse in tests of working memory, verbal memory, and attention.
- Participants were comparable in areas of perceptual reasoning, processing speed, and verbal comprehension.
- **Suggest early screening and intervention to identify those at risk for deficits in areas critical for academic learning.**

Guidelines for Psychosocial Services in Pediatric Oncology

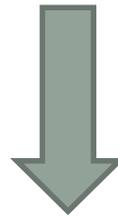


- In the 90's, a Psychosocial Committee of SIOP
- Publication of **guidelines for the provision of psychosocial services**, advocating for **provision of psychosocial support and education for all families**, the child with cancer, parents/caregivers and siblings

(Adam-Greenly, 1991; Masera, Spinetta, D'Angio et al, 1993; Masera, Spinetta, Jankovic et al, 1998; Spinetta, Jankovic, Eden et al, 1999).

Guidelines/Standards for Psychosocial Services In Oncology (cont.)

- The Canadian Partnership against Cancer (2009) promoted person-centered care and published the Guidelines for Implementing **Screening for Distress, the 6th vital sign**;
- Canadian Association of Psychosocial Oncology published the **Standard of Psychosocial Health Services for Persons with Cancer and their Families**, (2010, CAPO);
- The National Comprehensive Cancer Network (NCCN) published the **Clinical Practice Guidelines in Oncology to manage Psychosocial Distress** (July, 2015)



Patient-Centered Care

Standards for Psychosocial Care in Pediatric Oncology

- **Standards for Psychosocial Services in Pediatric Oncology** (IPOS/APOS, Washington, July 2015; PBC, Fall, 2015)
- Standards: **recommendations** to pediatric cancer centers **for the delivery of psychosocial care** (Guideline: specific information for making clinical decisions in the delivery of care).
- **Process**

In 2012 **The Mattie Miracle Cancer Foundation (MMCF)** facilitated a *Congressional Symposium* on Capitol Hill to address the current state of *pediatric psycho-oncology*. Legislators cited **the lack of established standards as an impediment to initiating legislation to make psychosocial oncology care an essential component of the medical care of children with cancer in US pediatric cancer centers.**
- **Project Leaders**

Founders of MMCF: Peter and Vick Brown
Scientific Team: Drs. Anne Kazak, Lori Weiner, Andrea Patenaude, Robert Noll & Mary Jo Kupst

Standards for Psychosocial Care in Pediatric Oncology (cont.)

(8 of 15 Standards presented here)

1. **Routine and systematic early psychosocial assessment and monitoring of psychosocial needs of youth with cancer and family** (*based on 149 studies, High (H)*)
2. Routine assessment and monitoring of neuropsychological deficits in high risk individuals during and after treatment (*based on 129 studies, H*)
3. Annual screening of psychosocial functioning of long-term survivors (*based on 101 studies, M-H*)
4. **Access to psychosocial support and intervention throughout the cancer journey** (*based on 173 studies, H*)
5. **Early and ongoing assessment of parents' needs for managing behavior and providing appropriate interventions** (*based on 159 studies, M*)
6. Provision of education and anticipatory guidance to child and family regarding diagnosis and treatment on an ongoing basis
7. Development of appropriate information about invasive procedures
8. **Provide appropriate supportive services for siblings** (*based on 117 studies, M*)

Conclusions and Recommendations:

1. It is important to screen for and identify “**early warnings**” of psychosocial risk and distress, not only in the child with cancer but the entire family.
2. Equally important is to identify **strengths or resilience factors** in the child and family to help them maximize their coping with the demands of cancer treatment
3. A pro-active, preventive approach can begin with the establishment of **a standard psychosocial protocol** for all families that includes psychosocial education-orientation and screening, ongoing monitoring and follow-up.
4. **Using the PAT** early identification shortly after diagnosis allows us to consider families as low, medium and high psychosocial risk, information that can be used to **allocate services and help families mobilize their resources in the family and community.**

Conclusions and Recommendations (cont'd)

5. **Ongoing screening, monitoring and follow-up** of psychological distress can be done, using a combination of **PAT** (shortly after dx, monthly? Every 3 or 6 months? yearly?, end of treatment?), **DT and PCCL** (at regular clinic visits?). Linked to psychosocial services
6. **There are challenges and barriers** at the institutional, team and individual level that need to be addressed with open dialogue (e.g. limited funding for psychosocial resources);
7. Each center needs to determine:
 - a) How best to establish a **standard approach** to improve psychosocial services and documentation;
 - b) How to open dialogue to implement change in psychosocial services;
 - c) Who would coordinate psychosocial screening, monitoring and follow-up, including documentation and dissemination of information obtained from the psychosocial screening instruments within the health care team; a **Psychosocial Navigator???**
8. Embrace Change: Opportunities to do things differently, to improve the psychosocial outcomes of children who are treated for cancer and their families.

Thank you very much!!