

Developmental and Psychosocial Aspect of Caring for Infants with Cancer: Psychosocial Care

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Goals for Today

- Discuss psychosocial care for families of children with cancer with a 12-month-old with high risk neuroblastoma in mind
- Describe psychosocial challenges that the family may face from diagnosis through treatment and beyond
- Discuss how all providers can address basic psychosocial needs of families
- Highlight roles of psychosocial providers including child life specialists, social workers, creative arts therapists, and psychologists

The Family Experience of Diagnosis

- Parents notice signs of fussiness, possible abdominal pain in their baby and when changing a diaper or playing, feel a lump in their belly – raise in anxiety, schedule a healthcare appointment
- Work-up by pediatrician, physical examination, diagnosis may be uncertain, then blood work, x-ray, referral to oncology – more anxiety
- Additional diagnostic tests (scans, bone marrow aspiration), assessment of metastases – more anxiety
- Receive diagnosis – shock, denial, fear, devastation

The Family Experience of Starting Treatment

- Overwhelmed with information and need to make decisions regarding treatment, possible clinical trial enrollment
- The patient and treatment become the center of the family's life
- Roles and responsibilities within the family and community (career) must be reorganized to meet the demands of treatment
- Need to adjust to new healthcare team; learn new vocabulary
- Need to manage own strong emotions along with those of family members

The Family Experience of Treatment

- Getting a plan in place and routines established helps stabilize the family and patient
- Assessments of treatment progress/outcomes, transitions in treatment from one stage to the next are stressful
- Ups and downs in the baby's physical state, mood and behavior may greatly influence the parents
- Concerns about being a good parent (e.g., protector, provider, advocate) may arise
- Need to care for oneself may take a back burner

The Family Experience of Ending Treatment

- Combination of elation and fear
- Concerns about relapse; no longer “actively fighting” cancer; loss of support of treatment team
- Transition to survivorship care; concerns about late effects; long-term outcomes for their child
- Need to establish a new normal; return to the community; re-establish family patterns and routines, social network

How All Providers Can Help

- Adopt a “trauma-informed” approach to care (Marsac et al., 2016)
 - Recognize that diagnosis and treatment for childhood cancer is a potentially traumatic event for families – their reactions are due to what is happening and has happened to their family in the past, not due to problems within their family
 - Symptoms of traumatic stress reactions include: intrusive thoughts or other forms of re-experiencing; negative thoughts and feelings about oneself, others and the world; avoidance; and, arousal – these are normative and (typically) adaptive reactions
 - Strive to minimize the potential for medical care to be perceived as traumatic
 - Provide education/preparation regarding what will happen through clear and open communication meeting the preferences of the family
 - Acknowledge and address distress; encourage coping resources (e.g., social support, respite care)
 - Refer to psychosocial providers when you have a concern about a family

How Psychosocial Providers Can Help

- Involve members of the Social Work team from the beginning
 - Meet with the family early; explain role
 - Prepare family for diagnosis/treatment discussion; attend meeting
 - Throughout treatment, identify and connect family to available resources
- Integrate Child Life and Creative Arts Therapies (e.g., music, art) into care
 - Provide developmental support; aid in coping with treatment
 - Model interactions/play behaviors for parents to use with their children
 - Set routines and behavioral plans as needed

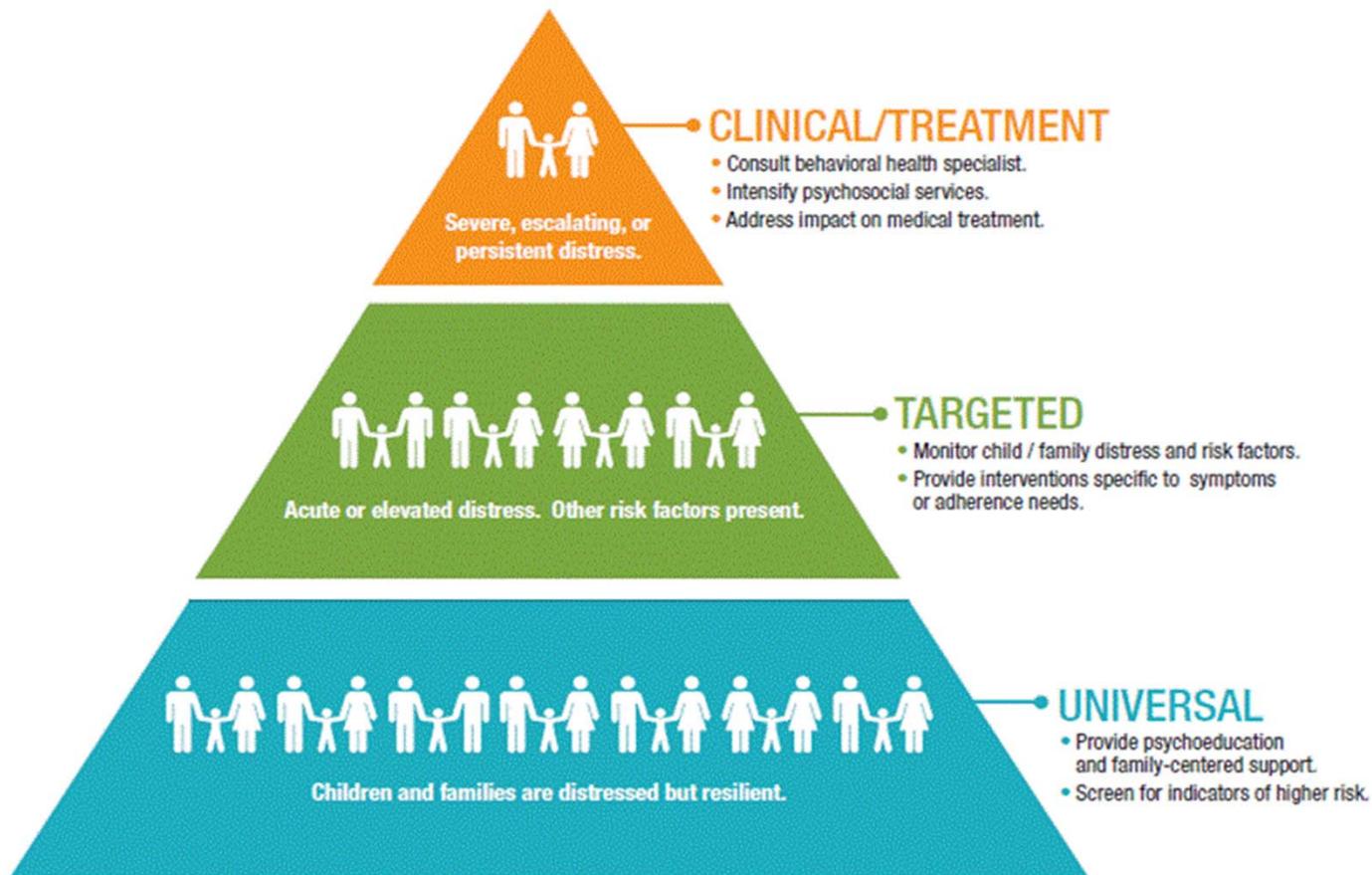
How Psychosocial Providers Can Help

- Assess level of psychosocial risk of the family
 - Standardized tools are best: Psychosocial Assessment Tool (www.PsychosocialAssessmentTool.org)
 - Helps identify pre-existing risks and resources of the family that may need further evaluation and intervention
 - Repeat administrations can help identify new issues as they arise

The Psychosocial Assessment Tool

- A brief parent report screener
- Assesses risk and resiliency across multiple domains (e.g., family structure and resources, family problems, social support, child problems, acute/post-traumatic stress, sibling problems)
- Scores map onto the Pediatric Psychosocial Preventative Health Model (PPPHM; Kazak, 2006) which provides a tri-level determination of family risk (Universal, Targeted, Clinical)
- Level of risk has implications for treatment recommendations to support family adaptation and address problems

The Pediatric Psychosocial Preventative Health Model



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How Can Psychosocial Providers Help

- Monitor child development
 - Screening through standardized and normed parent-report measures
 - Formal developmental evaluation at beginning of treatment and again after treatment or when screen suggest difficulty
- Psychological consultations/evaluations of parents/families having difficulty adjusting and meeting the demands of treatment
 - Identified through screening, self-referral, or staff concerns
 - Provision of support in hospital; Referral to community providers as needed

How Can Psychosocial Providers Help

- Monitor family and child development throughout survivorship
 - Continued screening for psychosocial risk, distress, neurocognitive and developmental problems
 - Continue to identify community resources to help meet the family's needs throughout the preschool period
 - Social support through cancer community
 - Early intervention services through education system
 - Referral for other services/therapies as needed
 - Formal neurocognitive assessment prior to beginning school; Help establishing an IEP as needed; Identification of specific neurorehabilitation opportunities

Thank you for your attention!

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Optimizing Infant Development throughout the Cancer Journey



Vanessa Burgess, MScOT, OT Reg.(Ont.)

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Objectives

- OT role with infants in Oncology
- Patient issues
- Challenges for rehab
- Referral process
- Case studies
 - Brain tumor
 - Infantile ALL
 - NBL



Occupational Therapy

- “Why does my baby need Occupational Therapy? He doesn’t have a job!”
- “I know what a Physiotherapist is. What’s an Occupational Therapist? Aren’t they the same?”
- [OT on Jeopardy \(April 2015\)](#)
- In pediatrics work = play



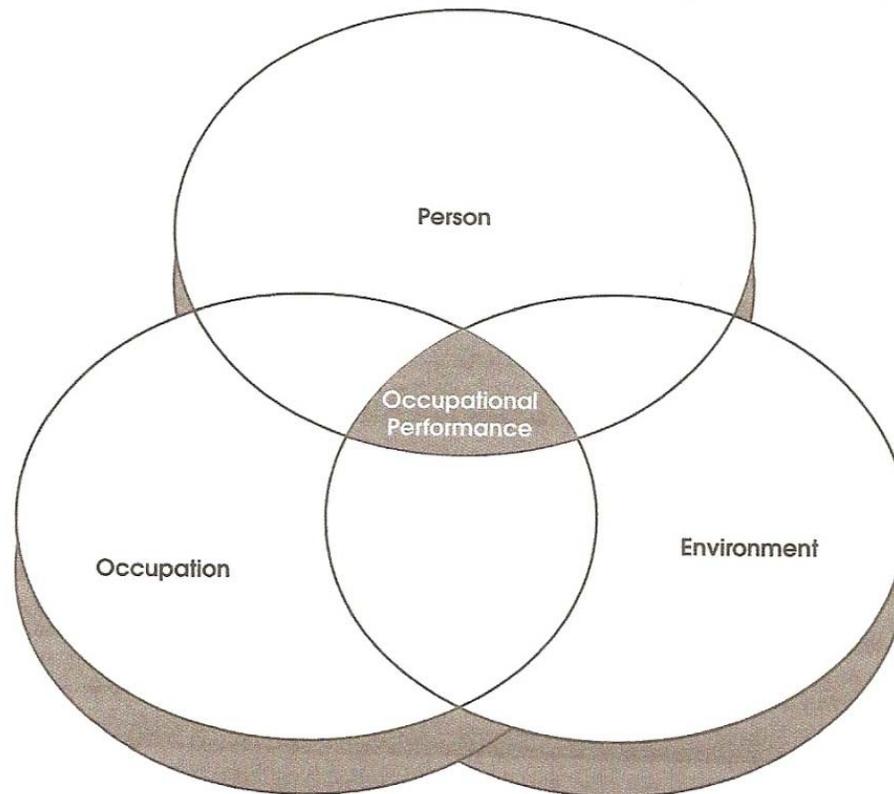
Primary Goal of OT

- To optimize patients' safety and functional ability during cancer treatment
- To enable patients' participation in self-care, productivity and leisure, throughout their developmental spectrum



PEO Model

Figure 2: Occupational Performance



(Adapted from Law et al, 1996. *Canadian Journal of Occupational Therapy*, 63, p. 18)
Enabling Occupation: An Occupational Therapy Perspective, CAOT 1997



Occupations for Children & Adolescents

- Self-care – oral feeding & swallowing, toileting, bathing, dressing, functional mobility
- Productivity – play, school, part-time jobs
- Leisure – social & community experiences with family & friends, games, sports



OT Role in Oncology

- OT role is 0.7 FTE
- In-patient ward
 - Pick up immediately if dysphagia symptoms & likely cancer Dx, even if path pending & MRP is surgical
 - Screen all patients, do not meet all
- Out-patient clinic
 - Active Treatment Clinic only
 - Do not service Off Treatment or After Care clinics – can consult
- Neuro-Oncology clinic
- Part of multi-disciplinary team – PT, RD, SW, CL, RN, NP, MD, Pharm, CRA



OT Role in Oncology

Assessment and Intervention for:

- Oral Feeding and Swallowing
 - Oral motor skills
 - Readiness for oral feeding
 - Risk of aspiration
 - Videofluoroscopic swallow study (VFSS)
 - Texture progressions
 - Feeding aversions
 - Sensory & behavioural feeding issues (i.e., “picky eaters”)



OT Role in Oncology

Assessment and Intervention for:

- Development – more than just milestones!
 - Transfers & positioning for comfort/cuddles & play
 - Developmental play skills
 - Gross motor skills – closely with PT partner
 - Fine motor skills
 - Visual–motor integration, perception & cognition
 - Sensory processing skills
 - Environment & exposures
 - Communication screen – query referral to SLP
 - +++Parent education

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OT Role in Oncology

Assessment and Intervention for:

- Central and Peripheral Neuropathies
- Neuropathies of varying degrees have been identified in 75% of children & youth treated for ALL (Gilchrist et al., 2009).
 - Ptosis – implications on play & functional mobility
 - Facial palsy & VC paralysis – implications for oral feeding & swallowing
 - Upper extremity - implications for play & self feeding
 - PT – Lower extremity – implications for mobility





OT Role in Oncology

Assessment and Intervention for:

- Equipment
 - Typical baby equipment
 - Adaptive equipment
- Discharge planning & home environment
 - Positioning in car seats
 - Transfers & play
 - Equipment



OT Role in Oncology

- Community Referrals
 - LHINs/CCACs - home
 - Children's Treatment Centres (CTCs)
 - By geographical area, services can differ slightly
 - In-patient Rehab – Holland Bloorview Kids Rehab
 - Community programs – input from medical team
- Equipment Vendors
 - Cancer Assistance Program (CAP)
 - Children's Treatment Centres
 - Assistive Devices Program (ADP)



Patient Issues

- Surgery
 - Brainstem, cerebellum, cranial nerves, vocal cords, hemiparesis, brachial plexus
- Treatment protocols
 - CIPN, VC paralysis – motor & sensory
 - malnutrition, mouth sores, tube feeding
 - fatigue, general malaise, somnolence
- Prolonged or frequent hospitalization
 - Environment, exposures, sensory processing



Challenges for Typical Development & Rehab

- Timing
 - Feeding, development
- Location
 - Inpatient vs. outpatient vs. home vs. CTC
- Equipment
 - Availability, sizing
- Environment
 - Physical, social



Referral Process – Who/When?

- All infants with brain tumors at Dx
- All infants with expected prolonged or frequent inpatient stays at Dx (ALL, NBL)
- All ~4-12 mo infants for oral feeding at Dx
- All infant/toddler “picky eaters” at Dx
- All ENT referrals for ?VC paralysis
- All ?sensory or motor CIPN



Referral Process – How/Where?

- Within multi-disciplinary team
- Inpatient
- Outpatient clinics
- Community – LHINs vs. CTCs
- Inpatient Rehab – Holland Bloorview
- Satellites – communicate issue to primary



Parents' Perspectives

- Development is a typical parental role
- Within their scope as a parent
- Bonding/Nurturing
- Differentiating normal development vs. infant's new normal d/t Dx
 - Feeding, play, comforting



Case Study – Brain Tumor

- “Andrew”
- Dx at 4 mo with congenital anaplastic ependymoma, Gr III, near total resection, R subdural-peritoneal shunt
- Uncoordinated oral motor skills, poor secretion management, risk of aspiration
- Plagiocephaly & torticollis
 - L head tilt – “favourite side vs. angry side”
- Delayed gross motor, milestones, poor head control



Case Study – Infantile ALL

- “Jonathon”
- Dx at 6 mo with HR infantile ALL, CNS 3
- Bottle fed well, starting pureed solids
- Refusal of bottle & decreased oral feeding
- Disliked prone d/t large belly, sitting with close supervision, reaching gross motor & fine motor milestones
- Fussy, difficult to get to sleep

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Case Study – NBL

- “Rebecca”
- Dx at 3 mo with HR NBL, Stage IV
- Abdominal distension, reflux
- Decreased oral feeding, vomiting
- Had thickened formula at home
- Delayed gross motor & milestones
- Fussy



Future Opportunities

- Increased role in Off-Treatment & After Care clinics & Survivorship programs
- Group therapy – ie, Pre-K & Kindergarten readiness
- Increased POGO & COG involvement
- Clinical research – oral feeding, infant development
- Canadian Association of Occupational Therapists (CAOT)
 - Network for OTs in Onc is mainly for adult oncology centres
 - Increase network in pediatric oncology centres
- Increased collaboration with community partners
 - CAP acquiring more pediatric equipment, provide information on patients' needs (ie, wheelchair & commode sizes)
 - Increased communication with satellite centres



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Thank You!

