

# Survivorship and the Family

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# IOM Report: Health and Behavior

- “Family members create a shared social reality that is linked to health and it is in this environment that most disease management takes place.”
- “A family-focused approach is likely to maximize intervention effectiveness”

# IOM Report: From Cancer Patient to Cancer Survivor: Lost in Transition

- Cancer's effects are not isolated to an individual. Instead, it has an impact on the entire family, and the needs of children, spouses, partners, and other loved ones all need to be considered. Family members routinely provide personal care and emotional support for the duration of the cancer experience. Financial concerns may also arise because family income, insurance status, and employment can all be profoundly affected by cancer. Caregivers and family members often require, but do not receive, the respite, health care, psychosocial, and financial assistance they need in meeting the many needs of cancer survivors in their lives.

# Cancer Quality Alliance: Blueprint for a Better Cancer Care System (2008)

- “Family involvement at outset and throughout care continuum”
- “Family involvement care is encouraged”
- “Patient navigation assists family with complex cancer care system”
- “Routinely assess cancer patients and their caregivers for side effects and psychosocial distress and when appropriate, refer to social work, mental health or other support services”

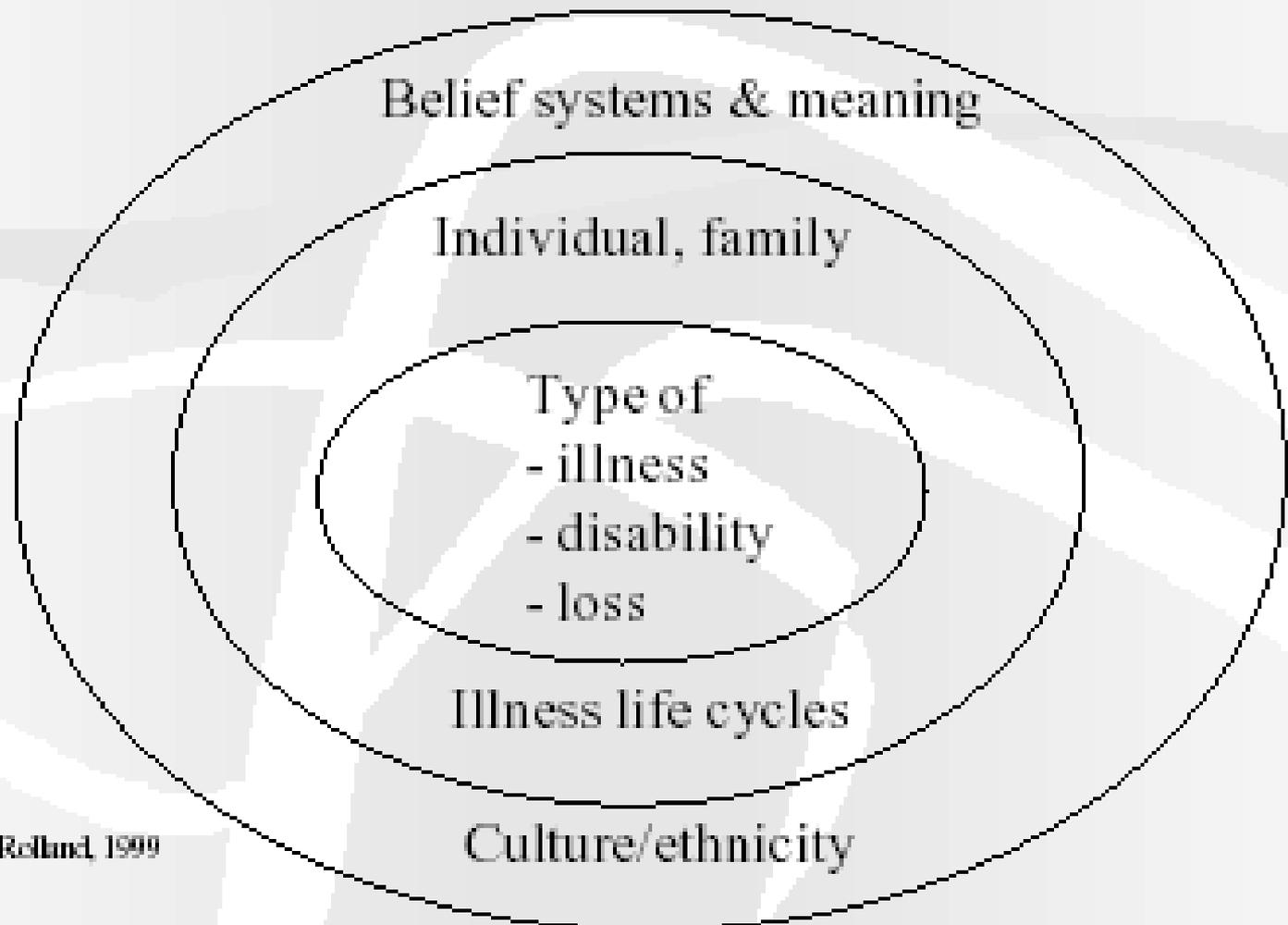
# Institute of Medicine Definitions of Family

- “A group of intimates with strong emotional bonds... and with a history and a future as a group”
- “A unique setting with powerful continuing relationships that assume levels of complexity and organization that go beyond the individual people involved.

# Family System

- The conceptualization of the family as a dynamic whole that is greater than the sum of its parts.
- Stability of system is essential for functioning (homeostasis)

# FAMILY SYSTEMS ILLNESS MODEL



Adapted from Rolland, 1999

# Family Life Cycle

- Developmental stages:
  - Independence -Single young adults leave home
  - Coupling or marriage
  - Families with young children
  - Families with adolescents
  - Launching adult children – Empty nest
  - Retirement or senior stage of life

# Family Contributions to Cancer and Survivorship

- Genetic predispositions to cancer
- Family socializes patient on views toward health, about when and how to use the health care system
- Family shapes health behaviors, such as smoking
- Family provides emotional support and guidance in stressful situations
- Family provides care and management for long term management of chronic illness

# Family Tasks in the Crisis (diagnostic) Phase of Cancer

(Rolland 1994)

- Family knows something is wrong and tends to pull together to cope with the symptoms in the medical system
- To deal effectively, families must reorganize temporarily to meet immediate needs; begin to address the task of accepting the illness; creating a meaning for the illness: deal with uncertainty

# Family Tasks in the Chronic Phase of an Illness

(Rolland 1994)

1. Family needs to accept the permanent change, grieve for the pre-illness identity and must negotiate new roles for chronic care.
2. Families need to try to live a normal life in abnormal condition.

# Common Family Problems in Cancer Survivorship

- Problems in Communication
  - Lack of communication
  - Inadequate communication
- Problems related to role-shifts
- Problems in support
  - Instrumental (household tasks)
  - Affective (fear, grief, loss)

# Sources of Stress in Families Experiencing Cancer

- Strained Family Relationships
  - Overprotective
  - Sibling rivalry
  - Tension and conflict in the marriage
- Change in Family Goals and Activities
- Increased Tasks and Responsibilities

# Practical Sources of Stress in Families Experiencing Cancer

- Increased Financial Burden
- Long term effects of treatments
  - Fatigue
  - Menopause
  - Body image
- Fertility
- Employment
- Social Isolation

# Cancer Survivorship and the Life Cycle of the Family

(Rolland, 1994)

- What are the normative tasks of the family at this stage in the life cycle?
- What is the nature of the illness and treatment?
  - Phase (crisis, chronic, terminal?)
  - Incapacitation?
- Does it allow the family (individual) to return to normal tasks?

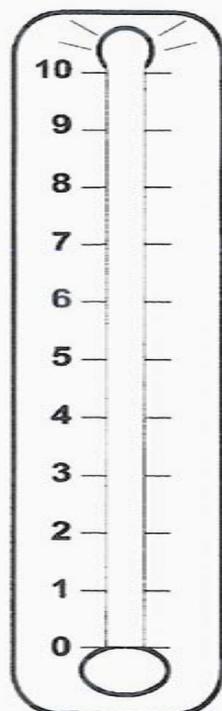
# Steps in Quality Management of Cancer Distress

- Screening
- Referral
- Assessment
- Interventions
- Follow-up / evaluation/ reassessment

## SCREENING TOOLS FOR MEASURING DISTRESS

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

Extreme distress



No distress

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES NO Practical Problems

- Child care  
  Housing  
  Insurance/financial  
  Transportation  
  Work/school

Family Problems

- Dealing with children  
  Dealing with partner

Emotional Problems

- Depression  
  Fears  
  Nervousness  
  Sadness  
  Worry  
  Loss of interest in usual activities  
  Spiritual/religious concerns

YES NO Physical Problems

- Appearance  
  Bathing/dressing  
  Breathing  
  Changes in urination  
  Constipation  
  Diarrhea  
  Eating  
  Fatigue  
  Feeling Swollen  
  Fevers  
  Getting around  
  Indigestion  
  Memory/concentration  
  Mouth sores  
  Nausea  
  Nose dry/congested  
  Pain  
  Sexual  
  Skin dry/itchy  
  Sleep  
  Tingling in hands/feet

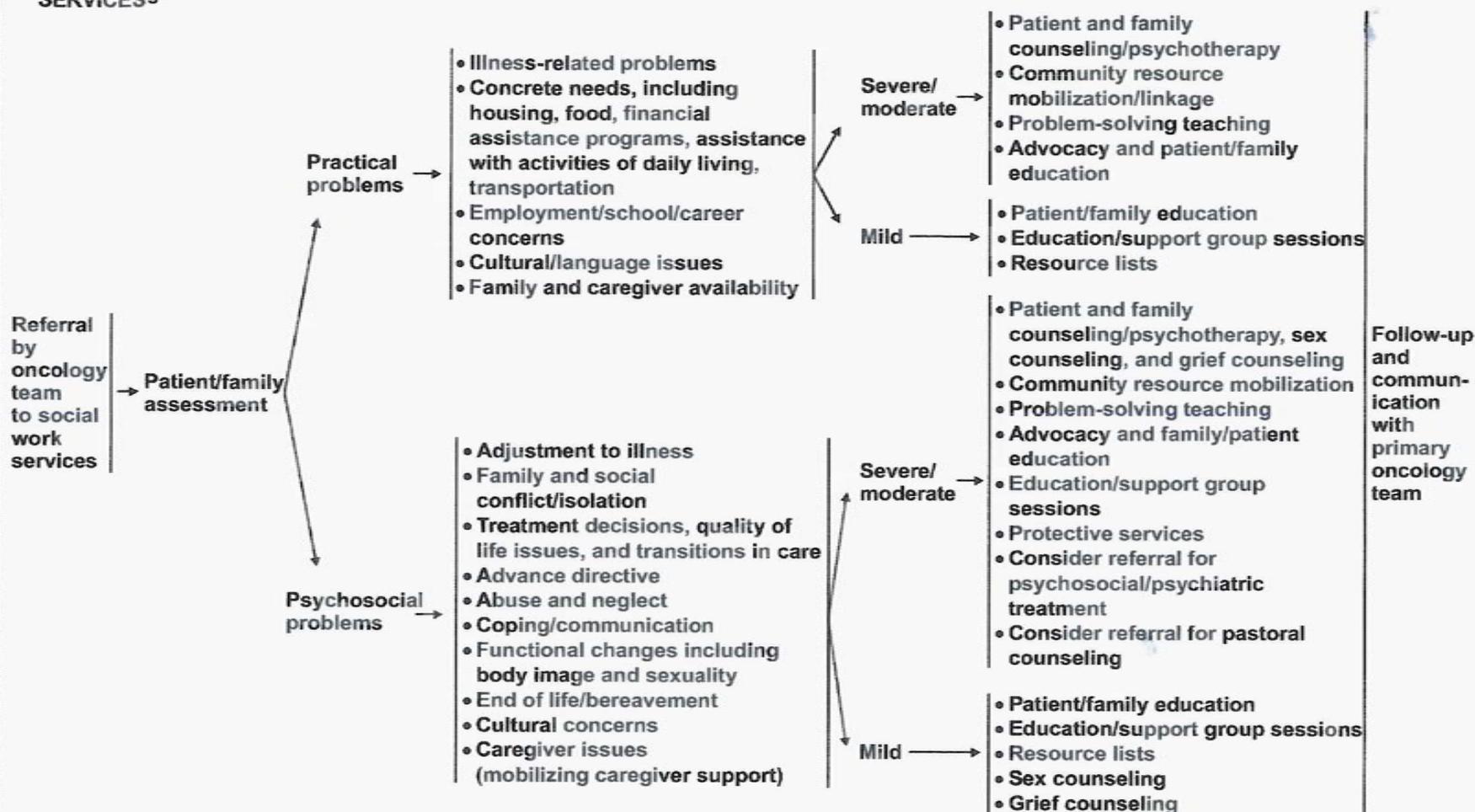
Other Problems: \_\_\_\_\_

**SOCIAL WORK SERVICES<sup>9</sup>**

**CATEGORY**

**TYPE OF PROBLEM**

**SOCIAL WORK INTERVENTIONS**



<sup>9</sup>Social work services include mental health services using psychological/psychiatric treatment guidelines.

**Note:** All recommendations are category 2A unless otherwise indicated.

**Clinical Trials:** NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

**See NCCN Palliative Care Guidelines**

# Family-Focused Interventions

- Few family-focused interventions have been studied for cancer patients and families
- Most studies are on diseases of childhood and adolescence
- Some are on dementia (Alzheimer's disease)

# Types of Family-Focused Interventions

(IOM Health and Behavior)

- Psychoeducational Interventions
- Interventions that affect family relationship quality and functioning
- Family therapy (for dysfunctional families)
- Reconfiguration of the health care team to incorporate working with families

# Psychoeducational Interventions

- Psychoeducation about cause, course, treatment of the disease, how disease affects individuals and family relationships over time, and how to access resources
- Cognitive and behavioral, problem-solving methods

# Interventions that affect family relationship quality and functioning

- Psychosocial interventions to strengthen relationships as a prevention intervention
- Multifamily groups
- Continuing Screening for psychological distress, family conflict, social isolation, followed by secondary preventive interventions
- Family support groups for primary, secondary and tertiary prevention

# Examples of Family-Focused Interventions in Cancer

- Psychoeducational Interventions
- Interventions that affect family relationship quality and functioning

# Issues in Family-Focused Cancer Care

- How is “family” defined?
  - Traditional family (married couple with children) has decreased from 40% of households to 25%
- Handling conflicting needs of family members and patient
- Accessing family members
  - We rely on patient’s report
  - Legal issues on who is the patient?
- Moving to a system of family-centered care