

Survivorship and the Family

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Presented at: Cancer Issues and Challenges
15th Maryland State Council on Cancer Control
Cancer Conference
Nov 12, 2008

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

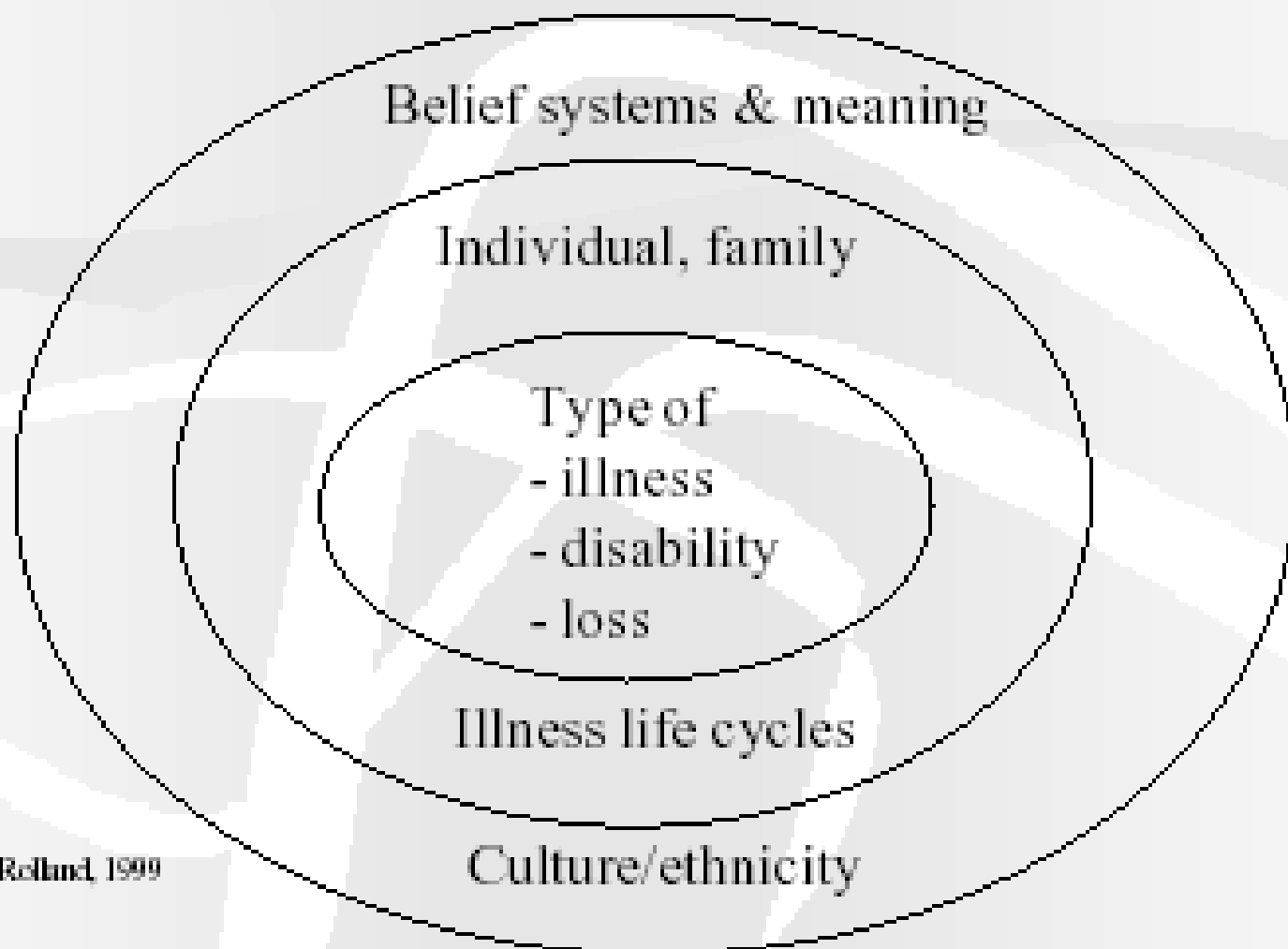
Definitions of Family

- “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?

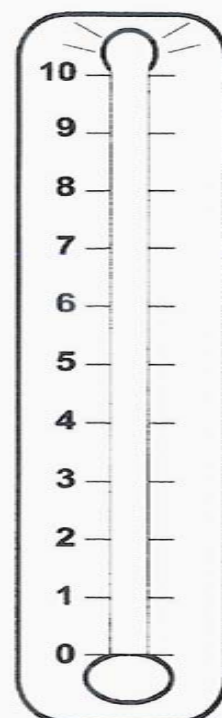
Steps in Quality Management of Cancer Distress

- 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

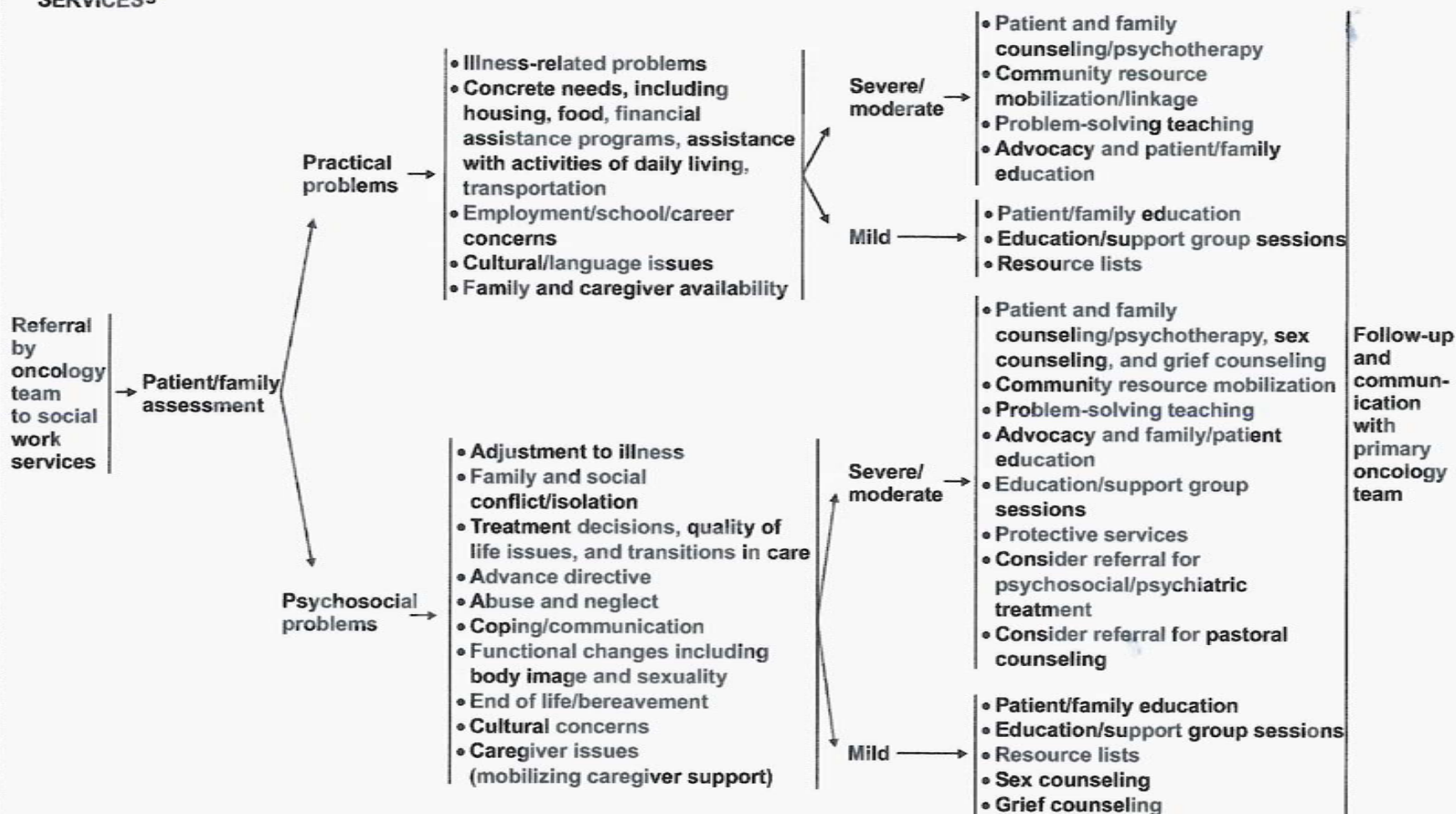
Other Problems: _____

SOCIAL WORK
SERVICES⁹

CATEGORY

TYPE OF PROBLEM

SOCIAL WORK INTERVENTIONS



⁹Social 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