

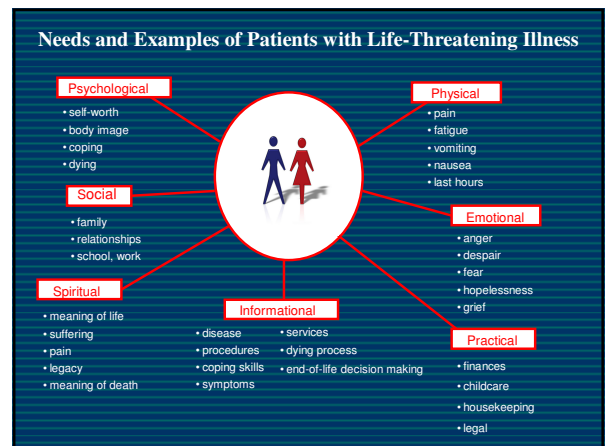
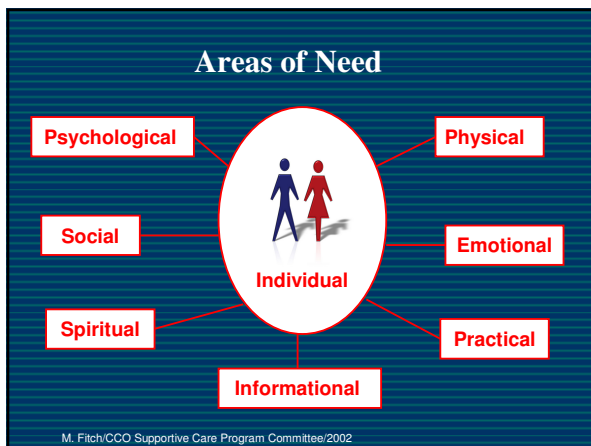
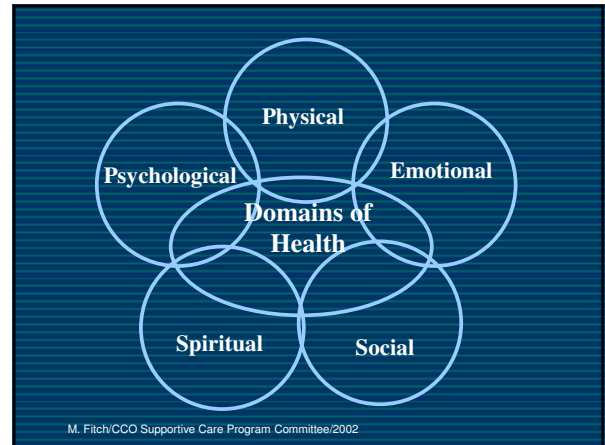
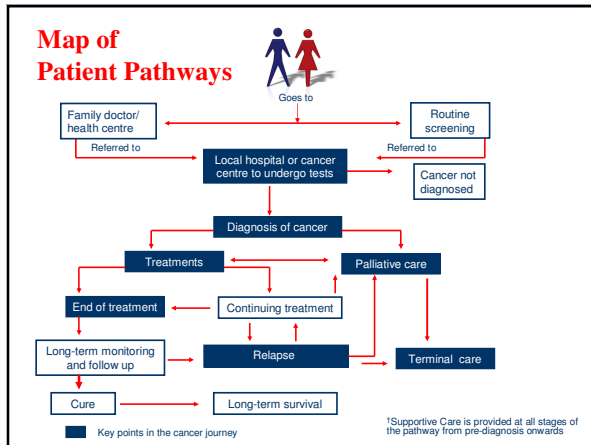
The Need for Supportive Care Patient/Survivor Perspectives:



Margaret I. Fitch, RN PhD

Purpose of Presentation

1. Highlight perspectives from cancer patients and survivors about their cancer experiences
2. Highlight implications for care delivery



Times of Transition

- finding an abnormality
- seeking an opinion/diagnostic testing
- hearing a diagnosis
- starting treatment
- finishing treatment
- getting back to normal
- being a survivor
- experiencing recurrence
- requiring palliative care
- approaching death
- dying...death
- grieving the loss

Prediagnosis (thinking something is wrong) (finding an abnormality/seeking help)

- knowing signs and symptoms
- seeking assistance
- being heard by healthcare professionals



Peridiagnosis (undergoing tests/waiting)

- preparing for and undergoing tests/procedures
- waiting for results/dealing with uncertainty
- access to information
- lack of control



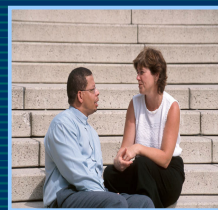
Diagnosis (hearing the definitive diagnosis)

- numbness, disbelief, panic
- "life is irrevocably changed"
- telling others



Treatment (knowing what is ahead) (making a decision)

- access to information
- thinking through implications
- who makes the decision
- waiting to begin/preparing



Treatment (undergoing treatment)

- starting
- dealing with side effects
- adjusting to cycles and patterns
- family disruption/adjustments
- finishing



Treatment (coping with multiple side effects) (making it through)

- pain, fatigue, difficulty sleeping, difficulty concentrating, menopause, skin changes, anxiety, bowel changes, sexual changes, nausea, vomiting, hair loss, weight change...



Rehabilitation (after treatment finishes) (getting back to normal)

- reflecting on what happened and what is ahead
- dealing with long-term side effects
- re-establishing life/living priorities
- fear of recurrence



Survivors

- A growing population
 - 60% of adults diagnosed are alive at 5 years
 - 78% of children diagnosed are alive at 5 years
- A vulnerable population
 - Spectrum of late complications
 - Lower health outcomes compared to peers
 - Less likely to receive care for range of chronic medical conditions

Survivors – Common Consequences

- Fear and uncertainty
- Changes in family roles
- Alterations in body image, self image
- Changes in comfort, physiologic functioning, mobility
- Alterations in cognitive functioning
- Changes in employment and recreation
- Alterations in sexuality, fertility
- Difficulties accessing on-going healthcare
- Increased risk for additional cancers

(Ganz, 2001; Aziz & Rowland, 2003; Denmark et al., 2005)

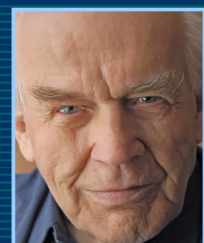
Recurrence (confronting repeat diagnosis)

- facing it all again
- access to information



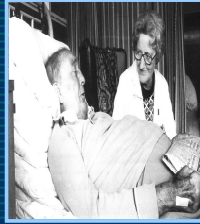
Metastatic Disease (living with uncertainty)

- What does this really mean?
- What is priority for me?
- What is priority for my family?
- Living with uncertainty



Advanced Disease (facing the end of life/approaching death)

- site of last days
- caregiver roles/responsibilities
- anticipatory grieving
- reducing symptom distress
- finding hope



Last Days of Living (focus on family)

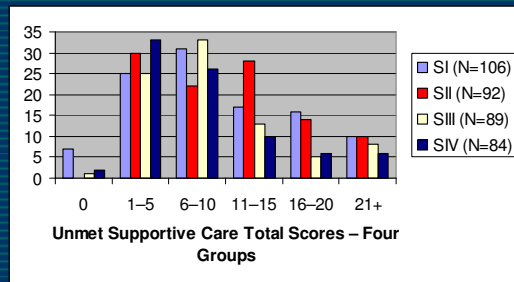
- Symptom management is key
- Support for family members



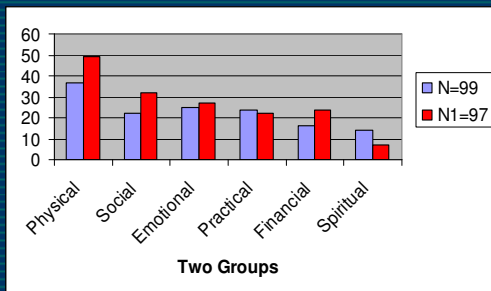
After the death (loss, grief and recovery)

- Acknowledgement of reactions (physical and emotional)
- Recognizing when bereavement reaction is unusual

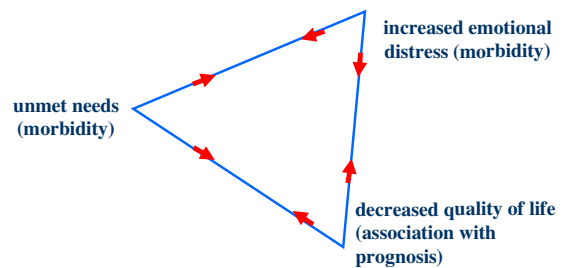
Scores Indicative of "Unmet" Supportive Care Needs



Proportion of Patients on Treatment (Mixed Sites) Expressing Distress Related to Specific Need Areas



Unmet Needs Influence Quality of Life



What we know

- Cancer and its treatment has an impact that may be felt in many ways
 - Individuals experience a range of reactions
 - Needs and responses can change over time
 - Interventions need to be tailored to the person's unique situation to be effective
 - Information, support and communication are critically important
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Proportion of Cancer Patients	Expertise Needed
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100%	Basic support and information Good communication
50-70%	Specific suggestions and encouragement
50%	Palliative care
35%	Expert psychosocial intervention
10-15%	Ongoing professional psychosocial intervention

What Do We Need to Do?

- Move what we know into practice
 - Work in partnership
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Increase Availability of Services

- Uneven distribution of programs/services
 - Scarcity of qualified human resources (professional and volunteer)
 - Appropriate programs may not exist (i.e., age, gender, culture etc.)
 - Need new ways to provide services (e.g., technology)
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Enhance Access to Services

- Patients/families knowing about services
 - Identification of those individuals wanting help (e.g., screening)
 - Easy (timely) referral processes
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Advocate for Necessary Care

- Recognition and valuing of broad range of needs patients/families/survivors can have
 - Education of health professionals and volunteers
 - Research to underpin service delivery
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Vision for a ReBalanced Cancer Care System

- Across the full range of illness-related events, cancer care is provided in a person-focused, compassionate and coordinated fashion.
 - Person-centered cancer care is provided throughout the treatment experience and beyond.
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