

Psychosocial assessment with patients and their families living with advanced cancer



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What do we know about
psychosocial needs of
patients and families living
with cancer?

The impact on the patient and family cannot be ignored



- Psychosocial problems can be created or exacerbated by cancer and the demands related to its treatment (such as financial pressures, role strain).
- Problems may also have been experienced before the illness (such as social isolation, poverty, substance use) and re-emerge or worsen.

Common Psychosocial Concerns



Practical

- **Concrete needs, including housing, food, financial assistance programs, assistance with activities of daily living, transportation**
- **Employment/school/career concerns (patient/ caregivers)**
- **Cultural/language considerations - Understanding health information**
- **Family and caregiver availability and skills**
- **Power of attorney, wills, planning for future of dependent(s)**
- **Location of last days (home, hospice, other)**

Psychosocial

- **Adjustment to illness, coping**
- **Impact on Family unit**
- **Treatment decisions, quality of life issues, and transitions in care**
- **Communication**
- **Functional changes including body image and sexuality**
- **Cultural concerns/considerations related to end of life care**
- **Caregiver issues (stress and burden)**

Psychosocial concerns



- Depression
- Anxiety
- Delirium

Potential problems before cancer diagnosis:

- Abuse and neglect (physical, emotional, financial)
- Family conflict
- Substance use/abuse
- Poverty
- Access to care issues (uninsured, medications)
- Social isolation
- Low literacy

Psychosocial Distress



“Distress can be seen as an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment.

It extends **along a continuum** from common normal feelings of vulnerability, sadness and fears, to problems that are disabling, such as true depression, anxiety, panic, and feeling isolated or in spiritual crisis”.



- What is the prevalence of distress in cancer patients?

Prevalence of Distress

- Prevalence estimates derived from large-scale studies with cancer patients typically exceed 30%.

Incidence rates of significant distress at all phases of cancer have been reported at 35% to 45% in North America

- Higher with advanced cancer



Fallowfield L, Ratcliffe D, Jenkins V, et al: Psychiatric morbidity and its recognition by doctors in patients with cancer. *Br J Cancer* 84:1011-1015, 2001

Zabora J, BrintzenhofeSzoc K, Curbow B, et al: The prevalence of distress by cancer site. *Psychooncology* 10:19-28, 2001

Carlson LE, Angen M, Cullum J, et al. High levels of untreated distress and fatigue in cancer patients. *Br J Cancer*. 2004; 90(12):2297-304.



- Patients screened using Brief Symptom Inventory (n=4496) at the Johns Hopkins Oncology Centre in Baltimore, MD, USA
- The overall prevalence rate of distress for this sample was **35.1%**.
- The rate varied from 43.4% for lung cancer to 29.6% for gynecological cancers.
- While some rates were significantly different, diagnoses with a poorer prognosis and greater patient burden produced similar rates of distress.
- Pancreatic cancer patients produced the highest mean scores for symptoms such as anxiety and depression.

Distress Screening as a Organized and Interprofessional Approach



“Screening for Distress, the 6th Vital Sign: A Guide to Implementing Best Practices in Person- Centred Care”

- Canadian Partnership Against Cancer

http://www.cancerview.ca/idc/groups/public/documents/webcontent/guide_implement_sfd.pdf

Person AND Family Centered Lens



Family members of patients with cancer experience higher-than-normal stress for multiple reasons, including:

- fear of losing their loved one,
- concern about the suffering of their family member, and the additional demands of providing emotional and
- logistical support and hands-on care during times of acute illness
- patient's ability to fulfill their own usual roles in the family is compromised



- What is unique about social work practice with those living with advanced cancer when compared to other areas of practice?
 - Needs of clients
 - Ways of working as a team
 - Knowledge or Skills
 - Impact on professionals doing this work

Special Considerations



- Past and Current Medical Situation
- Family's Structure and Roles
- Stage in the Life Cycle
- Cultural Values & Beliefs
- Patterns of Communication
- Socioeconomic Factors/Resources
- Past Experience with Illness, Disability & Death
- Coping History, Strengths

Past and Current Medical Situation

- Significant medical history
- Stage/extent of illness
- Current goals of treatment
- Current physical or psychological symptoms (e.g. pain, fatigue, depression, anxiety, delirium)
- Determine the patient's and family's understanding and interpretation of this information



- **Symptom Assessment (interprofessional)**

- Identify the presence of symptoms (pain, fatigue, etc.) and assess from a multidimensional perspective
- Determine the nature and quality of the symptom (e.g. Tools: Pain Scale, Pain Diary)
- What impact is this symptom having on the patient's quality of life?

Examples of Symptom Screening tools...



- **Edmonton Symptom Assessment System (ESAS-r)** (Bruera et al)
- Screens for the intensity of nine common symptoms experienced by cancer patients: Pain, Tiredness, Drowsiness, Nausea, Lack of Appetite, Shortness of Breath, Depression, Anxiety, Wellbeing ; Patients rate the severity of their symptoms on a scale of “0” to “10”.
- “0” = does not have the symptom; “10” = the symptom is at its very worst.

Psychometric Validation of the Edmonton Symptom Assessment System in Chinese Patients

Yixue Dong, Heng Chen, Yuanyu Zheng, Ying Guo, Jung Hye Kwon, En Liu, Hong Guo, Eduardo Bruera;
Journal of Pain and Symptom Management, 50 (5),A1-A22, B1-B8, e1-e2, 579-740 (November 2015)

Structure and Roles

- Who is in this family - both family of origin and family of choice?
- What roles have each member played in “health” and how will these be impacted under the strain of “sickness”?
- How does this family system function?

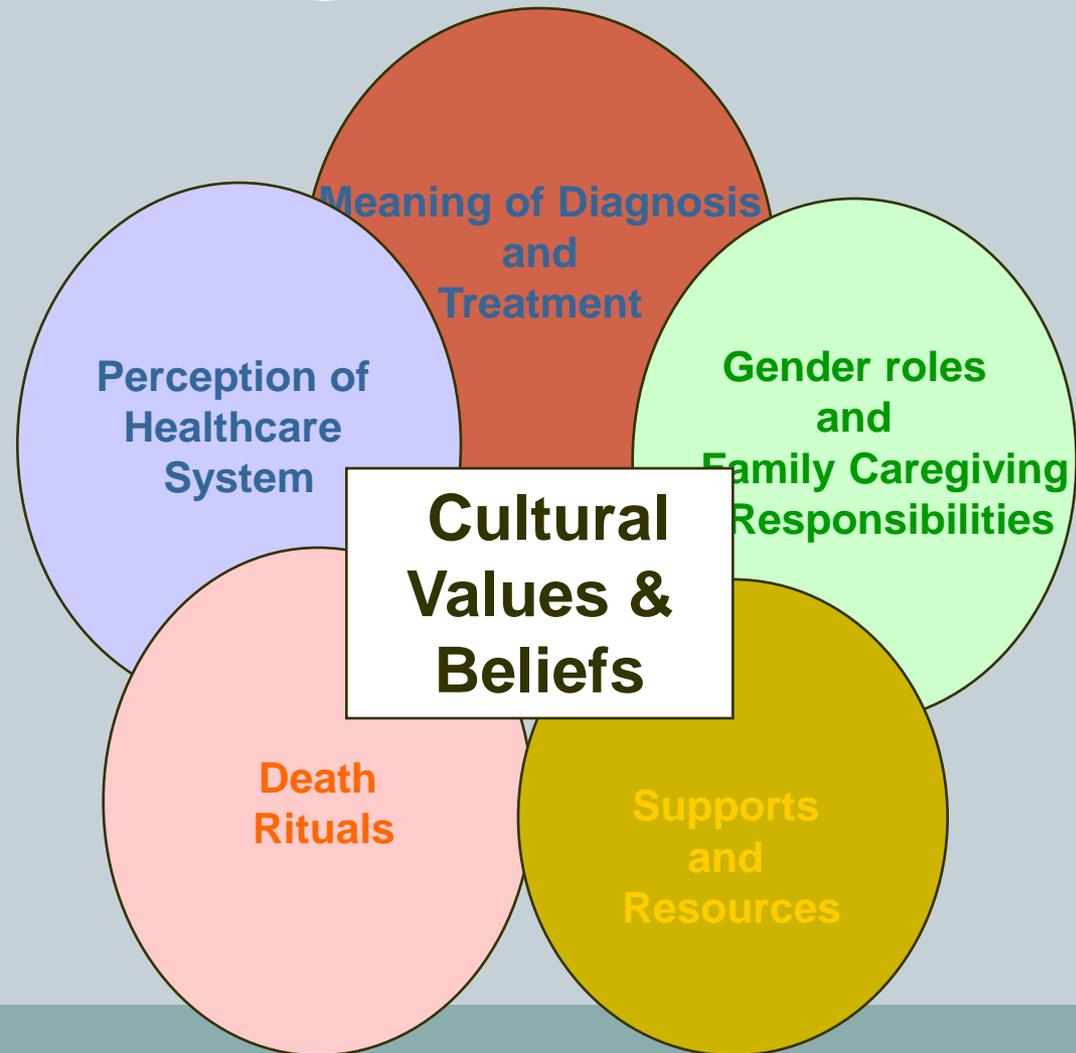
Stage in the Life Cycle

- How will the illness and treatment demands impact given this family's developmental stage?
- What losses are typically associated with this life stage and how will this situational crisis impact?

Cultural Values and Beliefs

- Identification of how cultural beliefs contribute to the individual's/family's understanding and coping patterns

Cultural Values and Beliefs Define the Family's Experience



Patterns of Communication

- Nature of communication in this family given the family's cultural context
- Considerations needing to be given regarding confidentiality and inclusiveness of family members
(e.g. sharing bad news, care planning)

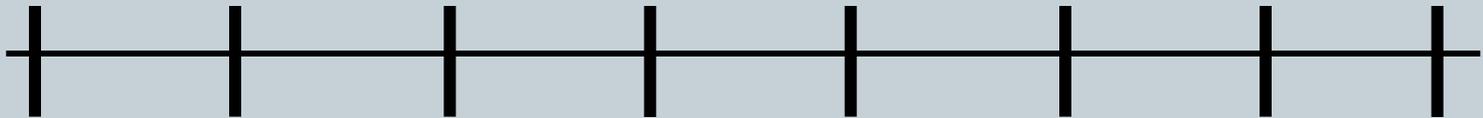
Socioeconomic Factors/Resources

- Resources (formal and informal supports) that this family has to enable them to manage this crisis
- Common problems:
 - ✦ financial strain
 - ✦ low literacy level
 - ✦ lack of insurance
 - ✦ lack of transportation
 - ✦ inadequate care-giving situation
 - ✦ inappropriate environment for safety at home

The Family's Experience Along the Illness Continuum



A family must deal with crises and losses at multiple points along the illness trajectory. It is important to understand this history to be able to help them in the here and now.



Pre-diagnosis

Treatment

Recurrence

Death

Diagnosis

Remission

Palliation

Bereavement

Past Experience with Illness, Disability & Death

- Family's past experience and coping with illness
- Resources accessed in the past that were perceived as helpful or not helpful (also identify forms of healing)
- Misconceptions that may come into play based on past experiences

Meaning of the Illness



- Individuals must create a “meaning” or understanding of events. Within a family, the meaning of illness may be different for each member. Meaning is influenced by many variables including culture.
- Example: Pain
- This is often the source of conflict within a family or between the client/team.
- Examples
 - “This is meant to make me stronger.”
 - “This is punishment. I am a bad person.”
 - “This is fate -these are the cards that I have been dealt in life.”

Coping History, Strengths

- Presence of past/current mental health problems or symptoms
- History of alcohol/drug use
- Previous use of supports (within family, community)
- Identified strategies for coping, accessing help, information
- Ability to communicate with health care team, navigate system

Social Work Practice



Screening, Assessment, Interventions

- Incorporating biopsychosocial history into the plan of care
- Exploring the cultural beliefs and values that requires clinician adaptation and accommodation
- Identify family structure, dynamics, and decision-making styles
- Planning and facilitation of family meetings
- Transition planning

Clinical Practice



Social workers possess expertise in areas of:

- Crisis Intervention
- Family work
- Navigating complex systems & accessing resources
- Psychosocial distress, grief and loss
- Psychological and social dimensions of symptoms related to illness
- Communication
- Resolution of conflict (eg. Ethical dilemmas)
- Cultural diversity

Research



- Contribution to the body of knowledge about the psychosocial impact of illness and death on families
- Evaluation of social work interventions and their effectiveness

Education



- Role of educator to clients (individuals, groups, community)
- Education of other health care professionals about the psychosocial needs and challenges facing those living with illness

What do social workers teach patients and caregivers?



- Psychosocial impact of illness
- Navigating health care and social systems
- Communicating with their health care team
- Communicating with each other as a family
- Completing advance directives
- Coping with/managing symptoms and distress
- Managing practical needs
- Effects of grief

Practical Dimensions of Care for Patients and Families

n Knowledge & Communication

- What to do for pain and other symptoms...
 - How to make decisions...
 - Who to call...
 - What to do after death...
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- **Institute of Medicine** (1997) Approaching Death: Improving care at the end of life. National Academy Press: Washington, D.C..Committee on Care at the End of Life

Physical Environment and Personal Care



- What to provide for immediate comfort and control...
- How to manage personal care...
- How to permit privacy or companionship when wanted...
- How to provide physical access and safety... Provide education about managing personal care

Family and Others Close to the Patient



- What to do for primary companion and caregiver...
- What to do for dependent children or other dependents...
- Who to be on-call in emergencies...



Financial and other Practical Issues

- How to handle short-term finances...
- What to do about longer-term finances...
- How to manage household...