# Enhancing Therapeutic Effectiveness

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## Diagnosis of cancer or life-limiting illness

- A person brings to their illness experience a number of factors that make this experience uniquely theirs, such as:
  - their age and the particular challenges of their life stage;
  - their gender;
  - the roles they play in their social and working lives;

## Diagnosis

- the relationships they have and how supportive or burdensome they are;
- their assumptive world including general world views and beliefs and cancer specific beliefs;
- the amount and efficacy of their social support;

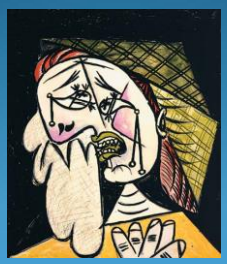
## Diagnosis

- their psychosocial history, including past losses, trauma and other significant experiences;
- their cultural background, including beliefs, customs, roles;
- their socioeconomic background, including the resources and choices available to them and their political and power status in their community.

## Importantly

- The patient is also viewed from within their family context (where family is defined by the client themselves) with a family-centred approach being crucial to comprehensive care.
- Indeed, cancer is viewed as a 'family experience', whereby family members are reciprocally affected by illness in each other (Northouse 1984; Quinn and Herndon 1986; Pederson and Valanis 1988; Zabora *et al.* 1990)

## Distress



- Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fear ….to

- problems that can become disabling, such as hopelessness, dependency, loss of control, uncertainty, worrying about the future, concern about being a burden, loss of dignity, depression, anxiety, panic, social isolation and spiritual crisis

(Chochinov, et al 2008; Chochinov, et al 2002; Wilson, et al 2007; Hack, et al 2004; Chochinov, et al 2001; Kissane, 2000)

## Domains of distress

- Distress is a significant problem estimates range from 20% to 50%
  - Physical
  - Psychological
  - Social
  - Spiritual

Kendall et al 2011; Holland & Alici 2010; Ernstmann et al 2009; Strong et al 2007; Carlson et al 2004

## Physical domain

## What causes physical distress

- Symptoms
  - nausea, pain shortness of breath, tiredness, anorexia, vomiting and constipation
- Loss of function
  - self-care (feeding, dressing, bathing)

Priestman, 1984

## Physical distress (cont'd)

- Curtailment of activity
  - mobility (move indoors/outdoors walking, lifting, bending)
- Loss of role activities
  - work, school, household

Cassileth,1984; Foot, 1995

## Psychological domain

## Increased risk of psycho-social problems

- Younger
- Children under 21
- Single, separated, divorced, widowed
- Poor marital or family functioning
- Social isolation

Roberts,1994; Neuling, 1988; Bloom,1994; Gantz 1993; Schag 1993

## Psychosocial risk factors

- Low socio-economic status
- Past history of psychiatric illness
- Alcohol or drug abuse
- Other recent life stresses

## What causes psychological distress

- Lack of supportive confiding relationships with family and friends
- Other life events and social difficulties not directly concerned with the illness e.g. recent bereavement
- Poor relationships with healthcare professionals

Mor, 1994; Roberts, 1994; Ell, 1989

## How common is it

- 25-50% of women with advanced cancer have clinically significant levels of anxiety and depression
- Future prognosis, welfare of relatives

Hopwood 1991, Pinder 1993, Hall, 2000, Jenkins 1991

## Social domain

## Social distress

- Diagnosis can impact negatively on relationships
- Ranked as a major concern of women with advanced breast cancer
- Feel partner does not understand

Lewis, 1995; Mahon, 1990; Given, 1992; Spiegel,1983

## How common is emotional distress in families

- ½ of partners will have some symptoms
- ¼ will have severe symptoms
  - Fear, loneliness, isolation
  - A sense of helplessness
  - Lifestyle disruption
  - Uncertainty
  - Struggle with impending death

Blanchard (2000)

## Some assumptions

- Illness brings families closer together
- All families share the same management goals
- All families have the same decision-making style
- Kaplan (1976), Lansky (1978)

## Some assumptions

- All families have the same information needs
- The nuclear family
- Cultural differences

Derdiarian (1986)

## Family reactions to staff

Conflicting information

Families can feel less capable
Intellectually paralysed
Anxious
Angry

However,

Lack in medical knowledge and decision-making power is compensated for in intensity and commitment

## Staff reactions to family

- Staff may not accurately gauge the family's capacity
  - Underestimate family's ability to make a meaningful contribution to care
  - Overestimate and expect family to perform tasks for which they are emotionally or practically unprepared

## How families can react

- May become acquiescent
  - These are deemed "good" families
- But underneath are ambivalent
  - Disappointment
  - Anger
  - Blame
  - Emotions exaggerate, become unrealistic
  - Not amenable to discussion

## How families can react

- Some families (deemed "impossible" or "irresponsible") never acquiesce
  - Argue and negotiate at every step
  - Sometimes avoid issue altogether
  - Can abandon patient
  - Take them out of current mode of management
  - Doctor shop
  - Seek alternative treatments
  - Can convince patient to stop treatment e.g. pain medication

## Family dysfunction

- Families can subtly manipulate and co-opt staff into playing a role in pre-existing family conflicts
- Families with poor boundaries will induce staff to become over-involved with them
- Families who are closed and suspicious will induce a distant, guarded stance from staff

## Distress in children

- Developmental age of child influences adjustment
  - Disintegration of family
  - Guilt about own contribution
  - Vulnerability of well parent

Lewis, 1990; Christ, 1993; Nelson, 1994;

## Distress in adolescents

- Adolescents
  - Disruption to social networks,
  - Decrease leisure activities
  - Increased domestic responsibility
  - Daughters at increased risk
- Parents may fail to recognise distress

Clarke, 1995; Wellisch, 1991; Welch,1996; Issel 1990; Wellisch,1992

## Spiritual or existential domain

## Spiritual distress

- May present as physical or psychological
- Shares many features with depression – feelings of hopelessness, worthlessness and a sense of meaninglessness
- May exacerbate or be exacerbated by physical symptoms e.g. pain

Rousseau, 2000; Raphael, 1984

## Common spiritual issues

- Why do people live?
- Does life have meaning?
- Is there a higher power?
- Why do people die?
- Why do people suffer?
- Does death have meaning?
- Why is this happening to me?

Rousseau, 2000

## What to do?


## Physical distress

- Actively enquire about symptoms, particularly pain and fatigue
  - How comfortable are you?
  - Is there anything we can do to make you more comfortable

Chochinov, 2002

## Physical distress

- Provide patient and family with information
- Practical support services
  - Is there anything further about your illness that you would like to know?
  - Are you getting all the information you feel you need?

## Psychological distress

- Empathetic listening
- Actively encourage discussion of how the individual and his/her family are coping
  - How are you coping with what is happening to you?
  - Ask how family reactions are impacting on them

## Social distress

- Actively encourage discussion of disease impact on relationships, social life, family
  - Do you worry about being a burden to others?
  - Do you worry about how your family will cope without you?
  - Refer for grief/general counselling
- Encourage open communication and expression of feelings

## Social distress

- Discuss issues relating to death and dying
  - What are your biggest concerns for the people you will leave behind?
  - Are there things about the later stages of your illness that you would like to discuss?

## Spiritual distress

- Listen
- Spiritual assessment:
  - Do you belong to any specific religion, faith or community?
  - Is God or religion significant to you?
  - Is prayer, scripture, music, meditation or reading helpful?
  - Are any particular religious practices helpful?

## Spiritual

- Refer for pastoral care if appropriate
- Participate in particular practices
- Support, not convert
- Silence may be best

Chochinov 2002

## Grief a normal response to loss

- Loss of physical strength and well-being
- Loss of independence
- Loss of role
- Loss of interpersonal relationships
- Loss of sexual function
- Loss of physical integrity
- Loss of life expectancy
- Loss of control
- Loss of mental integrity
- Loss of safety

## The role of personhood

## Eliciting Personhood Within Clinical Practice

- Personhood is seeing people in terms of who they are rather than exclusively in terms of whatever ailment they have.
- Failure to acknowledged personhood is often the cause of patient and family dissatisfaction.
- Chochinov et al Jnl Pain & Symptom Management 2015

## Background

- Modern medicine is sometimes seen as impersonal and routinised, with little attention being paid to issues of personhood.
- Often blamed on mounting pressures and an focus on the "technical, evidence-based aspects" of care.

## Background

- Perceived lack of caring can undermine trust, jeopardise the quality of HCP relationships.
- Families are more likely to feel that their real concerns have not been heard, acknowledged or addressed, increasing the likelihood of complaints or even litigation.

## Background

- Lack of engagement may seem to protect clinicians from emotionally painful aspects of attending to patients
- However, it is often associated with HCP burnout and clinical ineffectiveness

## Dignity Question

- *"What do I need to know about you as a person to give you the best care I can"*

## Patient Dignity Question

- Term coined because of the association between sense of dignity and patients feeling known for who they are and what is important to them, rather than exclusively in the terms of their diagnosis

## Development of Model

- Training guidelines established
- Basic counselling competencies developed
- Few empirical models integrating expert clinical skills to address distress
- Elements of therapeutic effectiveness examined in a series of focus groups with Canadian psychosocial-oncology clinicians detailing how they communicate with and approach distressed patients with cancer
- (Chochinov et al. (2013). Health care provider communication: An empirical model of therapeutic effectiveness. Cancer. doi: 10.1002/cncr.27949)

## OPTIMAL THERAPEUTIC POTENTIAL

By skillfully combining elements contained within each of the domains, clinicians are able to achieve optimal therapeutic effectiveness.

## Enhancing Therapeutic Effectiveness

3 primary domains:

Therapeutic approaches
Creating a safe space
Personal growth and self-care

## THERAPEUTIC APPROACHES

grandfailure/Adobe Stock

- Clarify & name sources of distress
- Problem-solve Educate, inform client
- Debunk myths
- Reinforce client strengths & positive ways of coping
- Provide techniques (e.g., mindfulness, Therapeutic Touch)
- Advocate for client with the care team
- Foster positive relationships between client & family

- Elicit client needs
- Probe for feelings underlying events & circumstances
- Help client identify what they can & can't control
- Help client understand by mirroring & reflection
- Use silence to encourage client expression
- Explore image & metaphor Offer comfort through touch
- Acknowledge spiritual distress

## THERAPEUTIC PACING

Listen attentively
Hold or ground client
Keep client in the here & now
Maintain slow pace- don't rush therapy
Encourage client to talk about fear & distress
Normalize & validate client experience & distress
Use skillful tentativeness, i.e., 'purposefully hesitant' so as to be non-threatening

## THERAPEUTIC PRESENCE

Being compassionate & empathetic
Being respectful & non-judgmental
Being genuine & authentic
Being trustworthy
Being fully present
Valuing intrinsic worth of client
Being mindful of boundaries
Being emotionally resilient

## THERAPEUTIC HUMILITY

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Do not avoid emotion
Tolerate clinical ambiguity
Be able to explore difficult topics
Accept and honour client as expert
Be a catalyst for therapeutic change
Trust in the process
'Sit with' client emotional distress
Avoid urge to have to fix
Model healthy processing of emotion

## CREATION OF A SAFE SPACE

Chen Liu/Eyeem/Getty Images

Provide privacy
Provide calming environment
Assure confidentiality

## PERSONAL GROWTH & SELF-CARE

a_lev/Adobe Stock

Maintain a balanced life
Work at self-awareness
Acknowledge / work through our own fears
Acknowledge your own feelings of vulnerability or helplessness
Debrief with colleagues
Value professional development

## Conclusion

- No one has to die in the state of psychoanalytical grace
  - Few, if any, people die with all their complexes and neuroses worked through
  - Everyone dies more or less in a state of psychological intestate – leaving behind some loose ends Rando, Therese

Model of

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