



What Constitutes A Quality Care? A Qualitative Study into the End-of-life Trajectory among Patients with Advanced Cancer

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What Constitutes Quality Care?

THEORETICAL CONCEPTS

- **Quality of life**
 - A subjective appraisal of one's personal sense of well-being and satisfaction with one's current level of functioning
 - Physical, psychological, social and spiritual domains as four key dimensions (Corr & Corr, 2013)
 - Similar dimensions are found in WHO definition of palliative care
- **Total pain**
 - Include physical symptoms, mental distress, social problems and emotional difficulties
- An all-encompassing nature of care within a “whole-person” framework

Background to the Study

Nature

- An exploratory, longitudinal study conducted with home hospice care patients

Research Focus

- To examine the physical, social, psychological, spiritual well-being of patient and the changes, if any, over the course of illness

Sample

- 11 patients, aged ≥ 55 , receiving home hospice care service

Data

- A total of 25 interviews (mode: 3 interviews)
- Ave length of interview: 49.4 minutes (range: 28-84 minutes)

Background to the Study

Research Methods

- Qualitative interviews using semi-structured interview guides at three time-points:
 - Initial phase (within the first 4 weeks of referral)
 - Middle phase (significant deterioration of their disease)
 - Final phase (days before the eventual death)
- Objective indicators used to determine the three time-points:
 - Changes in the scope of management
 - Changes in the management of symptoms
 - Changes in the patient's functional status

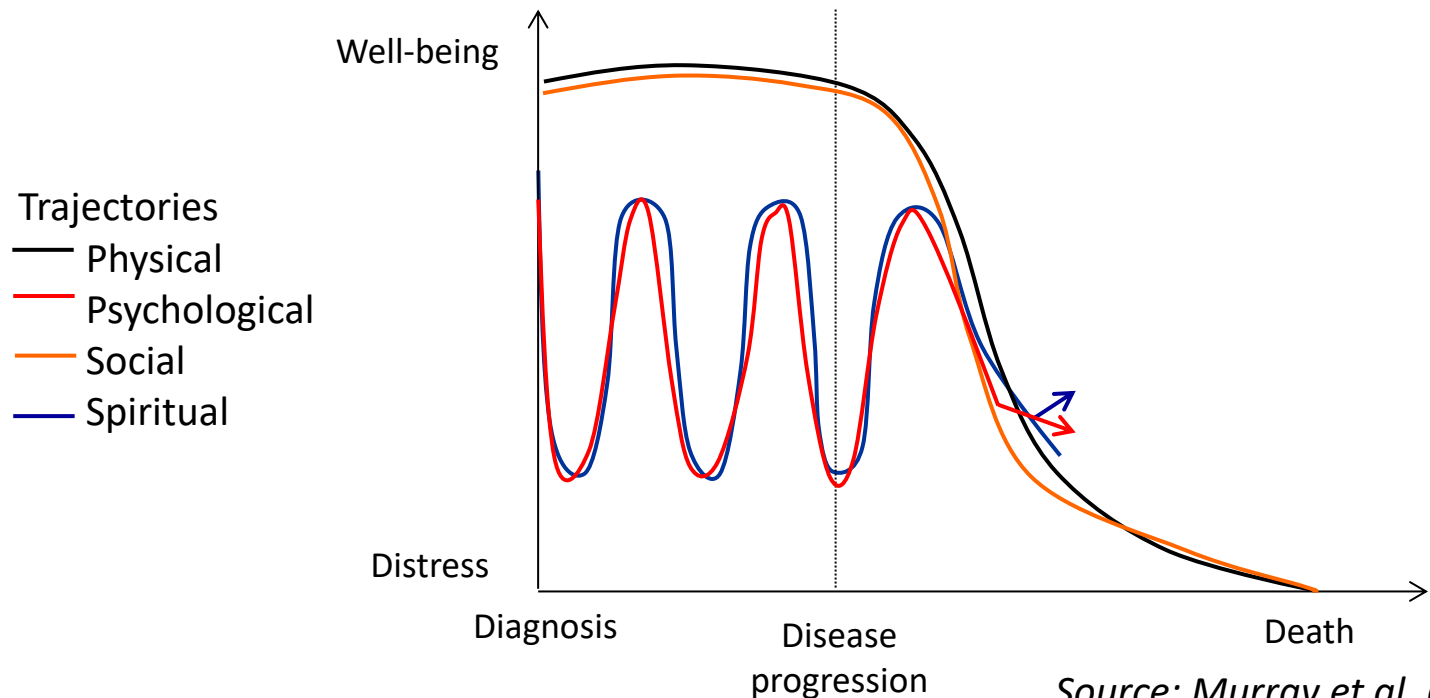
Analytical Method

- Narrative, thematic analysis

Findings and Discussion

Finding 1: Physical, psychological, social, spiritual aspects of end-of-life trajectory

- The lived experiences included physical, psychological, social, and spiritual aspects
- Multi-dimensional in nature



Source: Murray et al. (2007).

Physical, Psychological, Social, Spiritual Aspects of QoL

Domains of QoL	Disease Trajectory		
	Initial	Middle	Final
Physical	<ul style="list-style-type: none"> • Breathlessness • Constipation • Persistent cough • Limited mobility 	<ul style="list-style-type: none"> • Bloating • Weakening of vision • Fall • Pain 	<ul style="list-style-type: none"> • Deep fatigue • Infrequent urination • Bedridden • Pain
Psychological	<ul style="list-style-type: none"> • Fear • Anxiety • Uncertainty • Being positive 	<ul style="list-style-type: none"> • Fear • Anxiety • Uncertainty • Being positive 	<ul style="list-style-type: none"> • Fear • Anxiety • Uncertainty • Being positive
Social	<ul style="list-style-type: none"> • Family • Social network 	<ul style="list-style-type: none"> • Family • Social network 	<ul style="list-style-type: none"> • Family • Social network
Spiritual	<ul style="list-style-type: none"> • Hope • Lack of Hope • Meaning of life/death • Spiritual comfort 	<ul style="list-style-type: none"> • Hope • Lack of Hope • Meaning of life/death • Spiritual comfort 	<ul style="list-style-type: none"> • Hope • Lack of Hope • Meaning of life/death • Spiritual comfort

Finding 2: Dynamic Needs and Experiences

Domains - Sub-domain	Disease Trajectory		
	Initial	Middle	Final
Physical Well-being	<ul style="list-style-type: none"> • Breathlessness • Constipation • Persistent cough • Limited mobility 	<ul style="list-style-type: none"> • Bloating • Weakening of vision • Fall • Pain 	<ul style="list-style-type: none"> • Deep fatigue • Infrequent urination • Bedridden • Pain
Psychological Well-being - Fear	<i>Fearful of the “unknown” about the disease</i>	<i>Fearful of the “uncertainty” about life expectancy</i>	<i>Fearful of the occurrence and intensity of pain</i>
Social - Social connectedness	<ul style="list-style-type: none"> • Emotional support from friends 	<ul style="list-style-type: none"> • Care and concern from children and spouse 	<ul style="list-style-type: none"> • Ability to talk about “death preparation” with spouse
Spiritual Well-being - Hope	<i>Hope is to get well</i>	<i>Hope is to be able to make short trips</i>	<i>Hope is to have a timely death</i>

Finding 3: Dialectical Needs and Experiences

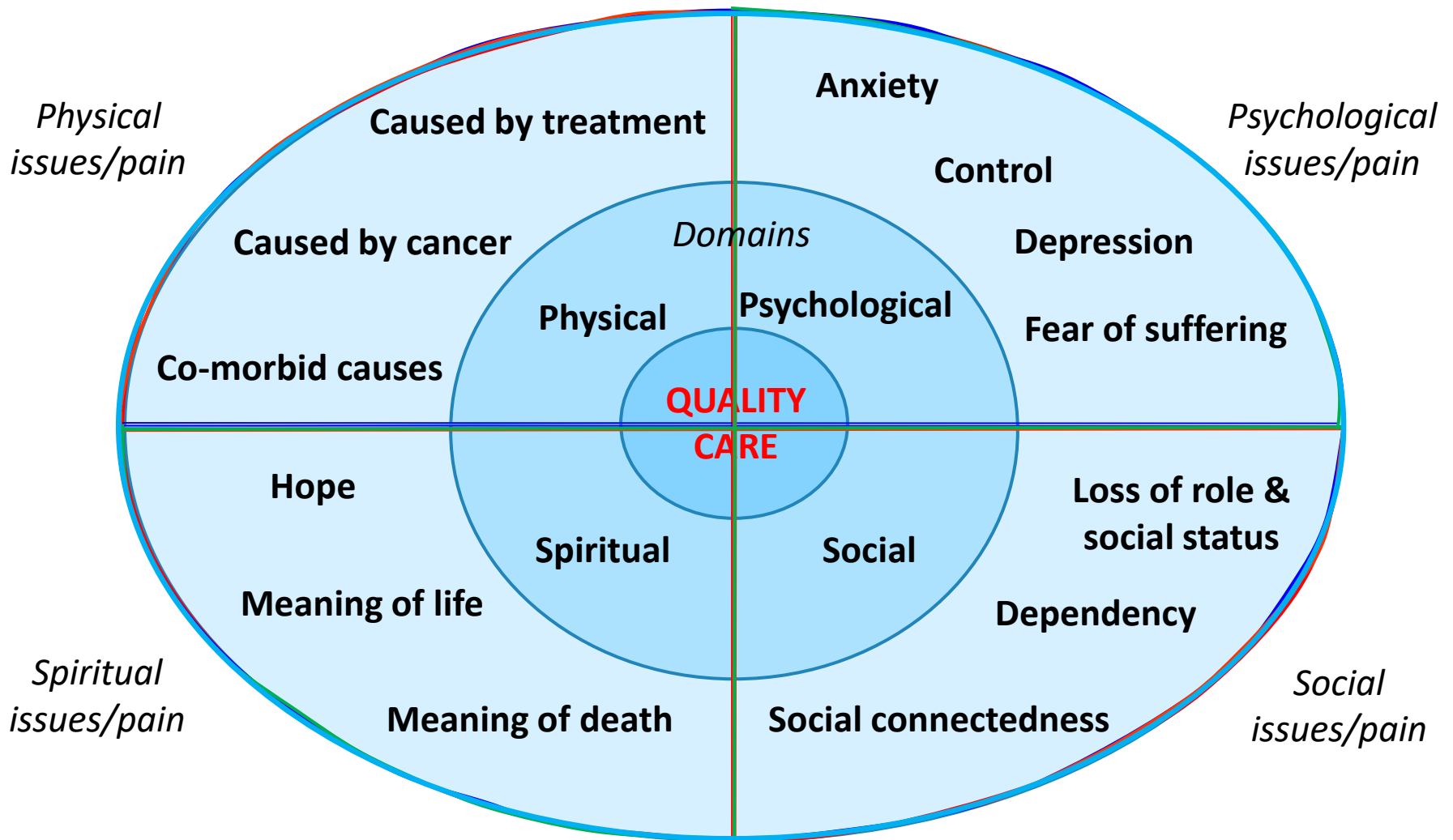
- Presence of dialectical nature of patients' experiences:
 - Presence, awareness and perhaps appreciation of opposition, systemic and yet continuous changing reality
- Examples of dialectical awareness
 - “Alive-death”
 - “Connectedness-isolation”
 - “Embitterment-acceptance”

Implications for Patient Care Provision at End of Life

Quality care

- Can be subjective and individual experience
 - Looking beyond pain and into the meaning of pain -> Suffering
- Requires dynamic and responsive patient care plans
 - An assessment, analysis and anticipative intervention plans from more than one angle
 - Assessment and re-assessment in response to changing needs and experiences

WHOLE PERSON FRAMEWORK



Reflective Conclusion

- Focus of end-of-life care is **NOT** on dying, but living.
- To explore innovative ways of helping the patients to live well in the final life chapter
 - Process and achieve a new equilibrium
 - Cope with the loss constructively
 - Manage the grieving process well
- To integrate the loss and grief so that one can **live well**, while also recognizing the need to **die well** for the dying person and to **grieve well** for the bereaved family

Thank You.
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