

Cross-Cultural Experience in Symptom Assessment



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Cross-Cultural Experience in Symptom Assessment

- Cancer patients frequently suffer from a myriad of symptoms
- Development and application of comprehensive assessment tools is essential to the effective management of these symptoms
- Assessment is the key for successful and effective therapy

Palliative Care

- Person-centered
- Symptom control
- Emotional support
- Decision-making
- Care planning
- Enhancement of quality of life

Patient Focused, Culturally Competent Health Care

It is much more important to know what sort of a patient has a disease, than what sort of disease a patient has.

Sir William Osler, 1911

Integral Elements of Culture

- Nationality
- Education
- Race
- Ethnicity
- Religion

Culture

... "the learned, shared, and transmitted values, beliefs, norms, and life way practices of a particular group that guides thinking, decisions, and actions in patterned ways."

Leininger

Cultural Assessment Skill

- Cultural assessment & cultural tools
- The process of learning how to conduct a cultural assessment

Cultural Assessment

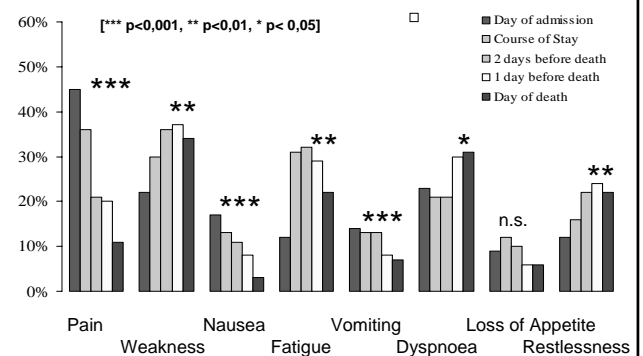
... “a systematic appraisal or examination of individuals, groups, and communities as to their cultural beliefs, values, and practices to determine the explicit needs and intervention practices within the context of the people being evaluated”

Leininger

Elements of Cultural Assessment

- Truth telling
- Family system
- Symptom control
- Rituals of death & dying
- Communication
- Withholding & withdrawing therapy
- Goals of care
- Personal issues

Symptoms of patients who died at our PCU (n = 249)



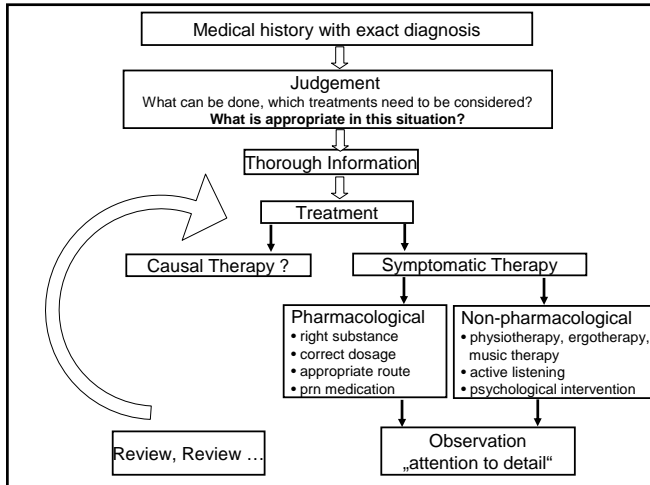
Nauck et al., J Cancer Res Clin Oncol 2002

Symptom Control

- pain
- other physical symptoms (nausea, vomiting, dyspnoea, itching, constipation, restlessness, anxiety, fatigue)
- psycho-social problems
- symptoms in the final phase (death rattle, sleepiness, pain, dyspnoea, restlessness)

Assessment of a “total symptom” ?

- Medical history
- Examination
- Cause of symptom
- Diagnosis of pathophysiological reason of the symptom
- Assessment of symptom intensity...



Assessment of a “total symptom” ?

Symptoms are individual and subjective experiences, comprising

- sensory-discriminative
- motivational-affective and
- cognitive-evaluative

dimensions.

Symptom Assessment

Measurement tool

- as simple as possible
- preferably self-assessment
- assessment conductible in interview technique
- not time-consuming

We do not see things as they are.

We see things as we are.

Talmudic Teachings

Cross-Cultural Experience in Symptom Assessment

- Patient-oriented evaluations using questionnaires have become an important aspect of clinical studies in palliative care
- Questionnaires must be translated and culturally adapted in order to be used in different language groups

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Translation

- In Europe it is usual for outcome measures to be translated into other languages
- Translation may be difficult and semantic problems may impede the discussion about definitions and assessment tools, for example with regard to the symptom of fatigue

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Translation

- The term 'fatigue', for example, is common in English and French, but did not exist in other European languages
- More research in the issue of cross-cultural validity is of paramount importance

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- Reliability and validity of the translated version must be comparable to the original version so that results from clinical trials in different settings can be compared

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- different assessment tools were designed specifically for palliative care patients, but
- cross-cultural validity needs to be determined before they can be applied in different cultural and ethnic settings

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Best Solution ?

Assessment "by the Ladder"

An approach to gain a total overview by looking into the matter step by step, thus sharpening the view for a patient's individual needs

and improving the overall quality of the practice of symptom assessment sustainably.

Assessment - **Step 1**

To determine the intensity of e.g. the symptom of pain

- visual analogue scales (VAS)
- verbal rating scales (VRS)
- numerical rating scales (NRS)

They are considered valid to assess pain and are used in many palliative care settings

Assessment “by the Ladder”

**Symptom
Intensity**
Unidimensional scales
VRS (verbal rating scale)
NRS (numeric rating scale)
VAS (visual analogue scale)

Symptom Assessment, **Step 1**

- part of the daily routine in clinical practice
- regularly and standardised
- in home care and clinical settings
- in cancer and non-cancer patients

Symptom Assessment, **Step 2**

Applicable to all patients with

- symptom intensity exceeding NRS 5
- insufficient symptom control
(reduction of intensity less than 30%)
- difficult and complex problems

Assessment “by the Ladder”

Pain Intensity
Unidimensional scales
VRS (verbal rating scale)
NRS (numeric rating scale)
VAS (visual analogue scale)

Symptom Experience
Multidimensional instruments
e.g. BFI (Brief Fatigue Inventory)

Symptom Assessment in Research

Assessment of quality of life

- POS (Palliative Outcome Score)
- EORTC-QLQ-C30 (European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire)
- SeiQOL (Schedule for the Evaluation of Individualised Quality of Life)

Reliable instruments to assess the quality of life, available in different language versions for use in different cultural settings

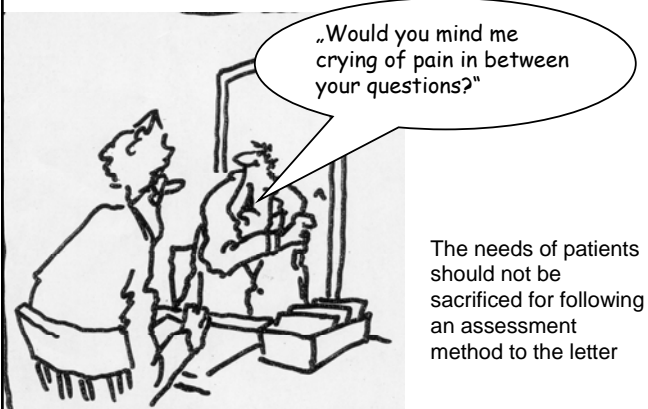
Symptom Assessment “by the Ladder”

Symptom Intensity
Unidimensional scales
VRS (verbal rating scale)
NRS (numeric rating scale)
VAS (visual analogue scale)

Symptom Experience
Multidimensional instruments
BFI (Brief Fatigue Inventory)

Suffering
Multidimensional questionnaires
POS (Palliative Outcome Score)
EORTC-QLQ-C30 (Quality of life)
SeiQOL (Quality of life)

Symptom Assessment



Relying on the steps only - tiny but vital things may be overlooked

If you look closer and closer at one aspect, you may miss the concept of the whole thing.

Problems of Symptom Assessment

- Self-assessment
versus
- Observer assessment

Self-assessment versus Observer Assessment

- low correlation in postoperative patients
- better correlation in nurses working in a pain clinic or with own pain experience
- doctors and nurses underestimate pain
- relatives overestimate pain

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- What to do in the future ?
- Is there a best solution ?

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- Despite differences among individuals and cultural groups, basic needs and preferences are common to all humans
- For truly effective palliative care, cultural subtleties and nuances must be considered

Cross-Cultural Experience in Symptom Assessment

- Assumptions based on one's own culture may be essential barriers to the development of knowledge and insight into the patient.
- Keeping an open mind about what is new or different within other cultures can extend and improve quality of palliative care.

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Take home message

- as simple as possible (different instruments for different situations)
- prefer self-assessment if possible
- assessment conductible in interview technique

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Take home message

- correlation with observer assessment
- education and implementation
-
but...

Weighing the Options

Professional
Integrity

Patient/Family
Wishes

Cross-Cultural Care LEARN

L = listen to patient's perception of the problem
E = explain your perception of the problem
A = acknowledge / discuss the differences / similarities
R = recommend treatment
N = negotiate agreement

“Hope is to see
in the eyes of
another that you
are understood”