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# UNDERSTANDING CULTURE, MEASURING EQUITY IN PALLIATIVE/EOL CARE

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# Cultural Aspect of Palliative Care

- Individuals draw meaning of terminal illness from cultural understandings of death and dying
- Their responses to it are shaped by the same cultural influences



# Fundamental Questions

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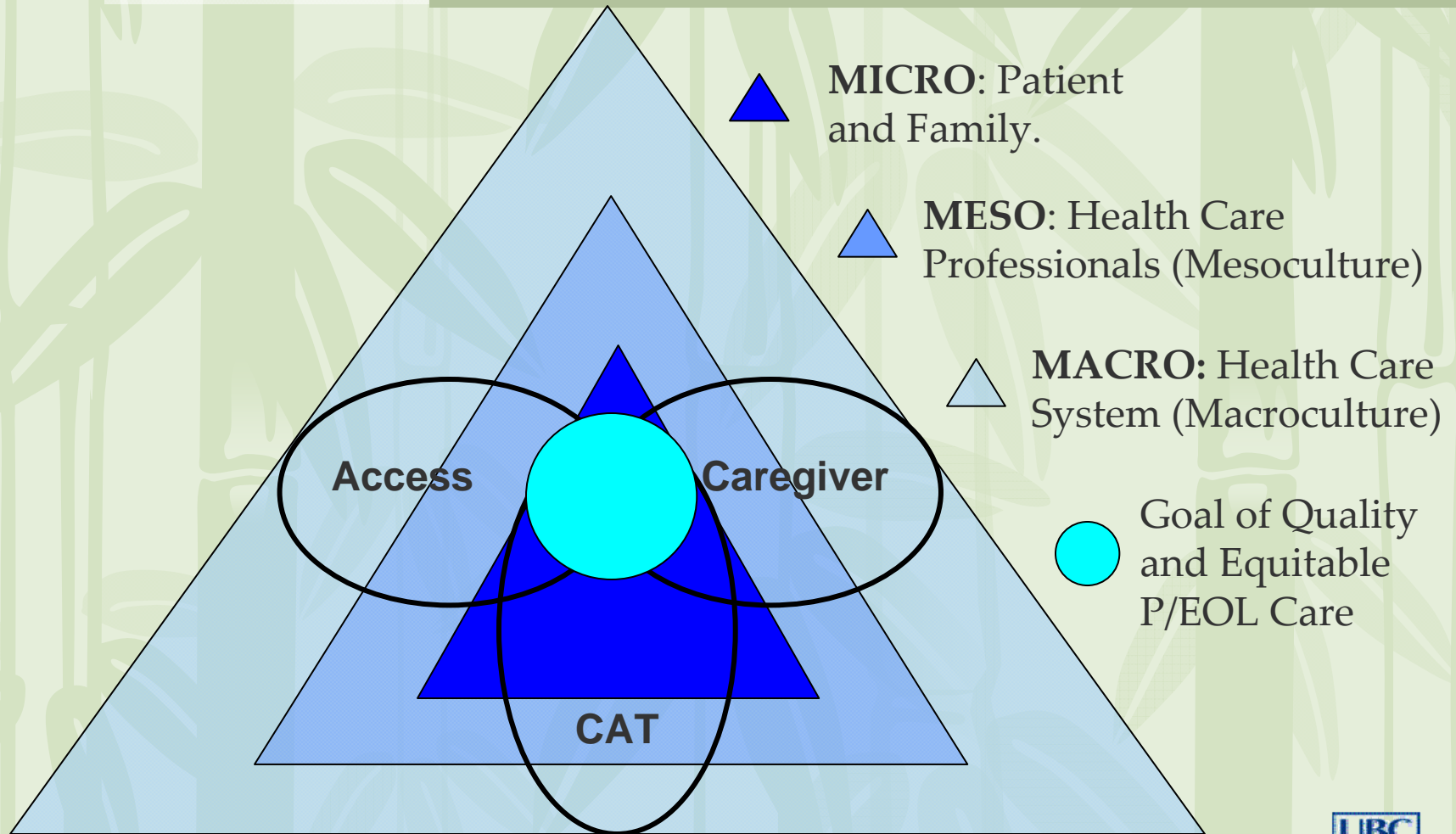
- How does culture shape one's understanding of the meaning of illness, suffering and dying?
- What impact does culture have on choices that patients make about caregivers, access to services, and symptom management?
- What impact does system culture have on quality of care?

# Workshop Objective:

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- To examine methods that delineate the influence of culture on access and utilization
  - What to measure?
  - How to measure?

# Micro, Meso, Macro –NET definitions



# What to measure?

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- *Micro culture* refers to:
  - the culture of palliative patients and family caregivers, and
  - the beliefs and practices about health and illness that they bring to their health care experience.
- Examples:
  - Attitudes toward truth telling
  - Life prolongation technology
  - Decision-making styles

# What to measure? – (cont'd)

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- *Meso culture* refers to the cultural values and practices of the health professionals providing palliative/end of life care, and
- *Macro culture* refers to system organization and capacity for cultural competency in health care.

# How to measure?

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- Quantitative approaches
  - Simple indicators
  - Complex indicators
- Qualitative approaches

# What does the literature say?

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- Key literature published from 2001-2006 in 11 electronic databases
- About 100 articles met pre-specified inclusion criteria; retrieved in full-text
- Now being critically appraised by 2 reviewers

# Literature – Cont'd

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- Empirical studies (60%): quantitative (33%) and qualitative (67%)
  - Utilization of services
  - Barriers to access
  - Advance care planning
- Conceptual articles (40%): theory development (70%) and literature reviews (30%)
  - Cultural competence
  - Decision making styles
  - Communication patterns
  - Ethics

# Literature – Cont'd

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- While some articles have attempted to define PC from essentialized cultural and ethnic perspectives, they tend to caution against the establishment of uniform cultural meanings of PC in light of diversity within specific cultural and ethnic groups. Accordingly, cultural definitions of PC within these studies vary in their scope and conceptual clarity.

# The Creation and Assessment of Indicators of Culture: Preliminary Work

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- BC Cancer Registry
  - No cultural information (e.g. ethnicity, religion, or language)
- How do we operationalize the conceptual definition of culture in the absence of cultural data?
- How do we define a neighbourhood?

# Two Solutions ...

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- Cut Point methodology
  - uses a single cultural attribute (e.g. South Asian Ethnicity) to define an area
  - understanding complex interplays of meaning may require overly complex models (statistically and clinically)
- Compression and clustering methodology
  - represents the construction of a measure based on the NET definition of culture rather than the utilization of a univariable proxy
  - uses the multinomial distribution of ethnicities in an area to identify neighbourhoods with similar characteristics
  - complex interplays of meaning are inherent in the indicator which allows form more tractable models



# Cut Point: Advantages and Disadvantages

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- Advantages
  - Uses freely available information
  - Easy to interpret
  - Quickly identifies neighbourhoods with desired attribute
- Disadvantages
  - No clear rationale for cut point selection
  - Populations of interest are identified by the research team which may influence the selection of cut points
  - Unclear classification of an area if multiple indicators are used (e.g. an area could be 50% South Asian and 25% East Asian and 25% European).
  - Demands interactions between all indicators for a cultural concept be included in the modelling procedure (e.g. need a three way interaction for the preceding ethnic mix as well as all two way interactions and all main effects).

# Compression and Clustering: Advantages and Disadvantages

- Advantages
  - Data driven
  - Researcher input enters at the end where interpretability of the results is critical for clinical use
  - Recognizes the complex interplay of cultural groupings that exist in a neighbourhood (DA)
    - This complex structure becomes an inherent part of the indicator
  - Cultural context is identified *after* the clusters are constructed
    - Minimizes imposition of researcher expectations or interests
- Disadvantages
  - Need a statistician
  - Interpretation can be difficult
    - Each resulting cluster is “best” described by an associated set of empirical distributions

# In Summary

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- The analytical methodology allows for a more comprehensive characterization of a DA composition.
- More information about a DA is possible.
- Provides an alternative way for classifying DA when working with complex variables.
- Groups are identified based on statistical analysis of data clusters.
- Future work will look at incorporating other dimensions of culture into the analysis.

# Assessment of the Cultural Dimensions of QOL using the Patient Outcome Scale (POS)

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- Interested in micro-cultural factors influencing QOL in palliative setting
- Using POS – Kings College London, I. Higginson et al
  - valid, reliable, responsive to change
  - quantitative design
- 2 study phases
  - Pilot – historical data
  - Prospective, longitudinal, multi-site

# Phase 1 - Retrospective Assessment of Cross-Cultural Dimensions of QOL in Palliative Cancer Care using the POS

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- Historic QOL data on 309 cancer patients attending BCCA Symptom Management Clinics
- Linked this to demographic data
- Used geographical location as proxy for ethnicity, based on StatsCan data
- Research questions:
  - Overall burden
  - Burden in specific domains
  - Correlation with demographics/ethnicity proxy

## Phase 2 - Patient Outcomes in Tertiary Palliative Cancer Care: A Prospective Assessment of the Cultural Dimensions of QOL Using the Kings College London POS

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- Prospective, longitudinal multi-site
- 400 patients in 4 Regional Cancer Centres and a Tertiary Palliative Care Unit
- Questions:
  - Does palliative cancer care make a difference to QOL overall and/or in specific domains?
  - Are there demographic/cultural indicators correlated to POS scores?
  - Can we identify which interventions are most effective and in which groups?

# Cross Cultural Outcome Tool Package

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- POS
- Demographic Data Form
  - i.e. DOB/gender/tumor type and stage/date of diagnosis/postal code/ECOG/treatment received
- Additional Demographic Form – cultural/ethnicity data
- Service Utilization Form
  - Inpatient/Outpatient/Multidisciplinary

# Additional Demographic Form

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- Where were you born?
  - If outside Canada, when did you arrive?
- What is the language usually spoken at home?
- Are you a visible minority group member?
- If above answer is yes, please check which applies:
  - Aboriginal/Black/South Asian/Southeast Asian/Chinese/Other-specify
- What is your marital status?
- What is the highest level of education you obtained?
- What are your living arrangements?

# Qualitative paradigm

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- Qualitative narrative inquiry aimed at understanding the lived experiences of specific cultural groups
- Perspectives and meaning are sought through the description of the direct experiences of the participants
- It is not a prediction of outcomes, rather a deeper and clearer understanding of people's stories

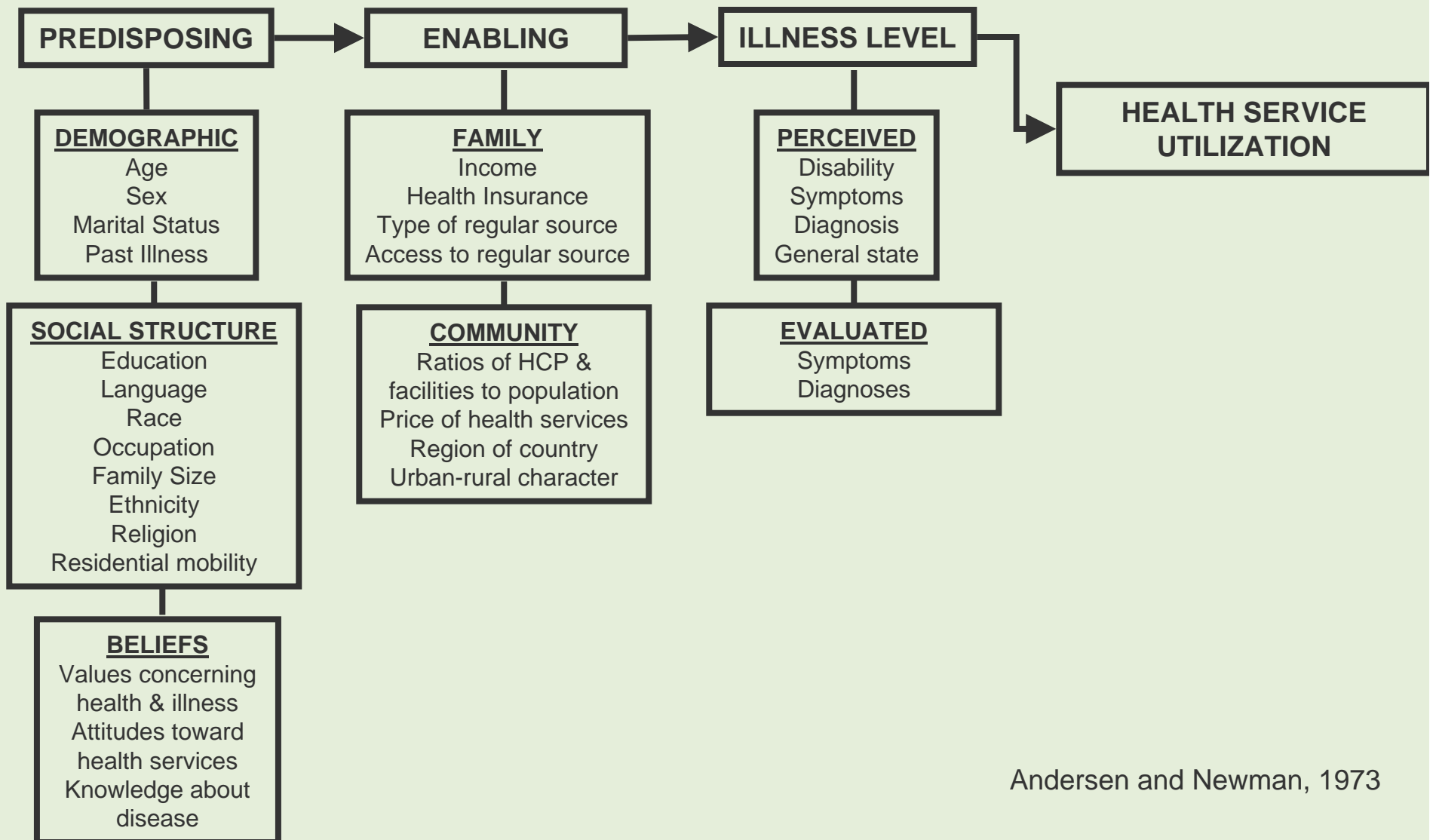
- Participatory in nature
  - For example, stories were collected from Elders, cancer patients and family caregivers around their own cancer experiences in their cultural context including their world view.
  - Four case studies were documented around the experiences of end-of life in Black Nova Scotians and their use of home remedies
- Selected ethno-cultural cancer patients and their use of CAM:
  - Black Nova Scotians (NS)
  - Woodland Cree (SK)
  - East-Indians (across Canada)
  - Chinese (BC)

# Use of TCM/CAM in Chinese cancer patients

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- One exploratory qualitative study was conducted to better understand issues faced by Chinese cancer patients in a Western healthcare context (BCCA) and also to inform the development of a survey in this population
- A prevalence study of use of TCM/CAM in Chinese cancer patients followed. **One of the objectives was to explore the differences between acculturated & non-acculturated patients.** A quantitative approach guided by the Andersen conceptual framework of health services utilization was used.

# Theoretical Framework



Andersen and Newman, 1973

# Cultural Factors Associated with TCM/CAM Use

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- Immigrant status (born outside Canada) and speaking Chinese at home were significantly associated with TCM/CAM use
- Completion of survey in Chinese showed trend towards significance
- Findings support effect of acculturation on use of TCM/CAM
- Future research should account for degree of acculturation in understanding CAM use

# Issues in Defining and Measuring Culture Research

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- Culture as “a complex interplay of meanings that represent and shape the individual and collective lives of people” is the definition adopted by this NET.
- Culture is often reduced to a single measure: ethnicity, language spoken at home, place of birth and time spent in Canada.
- Acculturation is not well understood within health research and difficult to measure.
- Necessary to promote research that transcends disciplinary boundaries and works with the populations of interest, using participatory methodologies.