

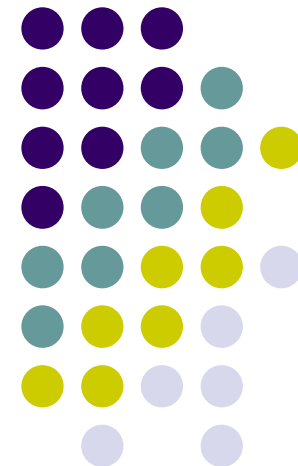
Kangaroo Mother Care for Preterm Infants

Measuring Health Related Quality of Life in Preterm Infants at 1 year of corrected age

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DEFINING HEALTH RELATED QUALITY OF LIFE (HRQOL)

Health related Quality of Life (HRQL)



- HRQOL metrics aim to quantify how a patient's illness and medical treatments impact their overall physical, social, emotional and psychological well-being.
- HRQL metrics is **key** for assessing the value of living life in different health conditions or discrete health states.

Health related Quality of Life (HRQL)



- HRQOL measures useful for:
 - Tracking health of patients and populations
 - Evaluating effect of interventions
 - Quantifying patient burden due to disease and subsequent medical interventions
 - Facilitating patient–family-clinician communication

Health related Quality of Life (HRQL)



- Three types of HRQOL measures:
 - Dimension-specific: focus on a particular element of well-being, (e.g. psychological health)
 - Disease(condition)-specific: multiple dimensions of health that pertain to a certain condition (e.g. cerebral palsy)
 - Generic: used across populations with different diseases, usually measure physical, psychological and social domains of health



HEALTH RELATED QUALITY OF LIFE MEASUREMENT IN PREMATURE INFANTS



Review of evidence

- Infants' HRQOL construct and methodology are complex:
 - Diverse developmental and emotional stages underlying children's health and disease states
 - Measured by proxy
 - Parents and other adults
 - Health care providers and experts
 - Centered on Disease and Disability



Review of evidence

- Solans et al*. systematic review:
 - Identified nearly 100 pediatric HRQOL measures
 - All of them based on self or parents report
 - One-third were generic
 - Two-thirds were disease (condition) - specific.
 - Only two involve infants (1 to 5 years)
 - None of them related to prematurity

* Solans M, Pane S, Estrada M-D, Serra-Sutton V, Berra S, Herdman M *et al.* Health-related quality of life measurement in children and adolescents: a systematic review of generic and disease-specific instruments. *Value Health* 2008; 11: 742–764.



Review of evidence

- Supplementary search in Pubmed
 - 26 References of HRQOL measurements and prematurity
 - Only two are directly relevant to measuring HRQOL in premature infants
 - Derivation and validation of the TNO-AZL Preschool Quality Of Life (TAPQOL)
 - Use of TAPQOL in former prematures 1-4 years old
 - All other describe HRQOL in former prematures at school age to adolescents and young adulthood



Review of evidence

- TNO-AZL Preschool Quality Of Life (TAPQOL)
 - 4 Domains:
 - Physical
 - Social
 - Cognitive
 - Emotional
 - 12 subdomains
 - 43 Items
- Health inventory, does not measure preferences nor utilities

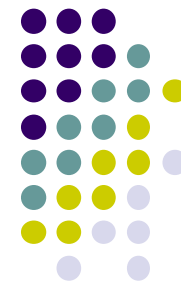


HRQOL AT 1 YEAR OF AGE AND KMC



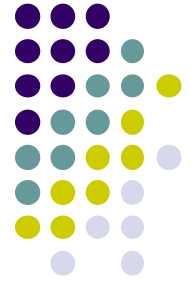
Health inventory and KMC

- Identification of pertinent domains
 - Dimensions of health that affect infants quantity and quality of life
 - Can be affected by the KMC intervention
- Measured outcomes for the 1991-1994 RCT on KMC in Bogotá were candidates



Health inventory and KMC

- They fall into three main domains:
 - Disease-based outcomes
 - Health related outcomes
 - Patient and family wellbeing related outcomes
- Disease-Based outcomes
 - 1 year Mortality
 - Infectious morbidity



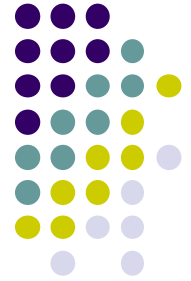
Health inventory and KMC

- Health related outcomes
 - Growth and development
 - Feeding patterns
- Wellbeing related outcomes
 - Mother feelings and mood
 - Mother-infant bonding
 - Quality of family environment
 - Father involvement



Health inventory and KMC

- Because of lack of population-based reference standards, none of the Wellbeing related outcomes could be included
- A health state inventory was developed, and weights (utilities) were assigned by clinical experts



Health inventory and KMC

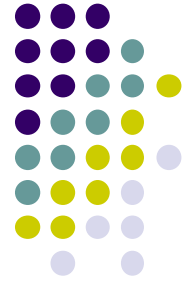
- Experts took into account
 - Disability
 - Severity
 - Burden (emotional, physical) for infant and caregivers
- Two systems were employed.
 - Multi-attribute utility function (additive)
 - Direct ordering and scoring

Multi-attribute utility function



- Seven items (study outcomes) were included
 - Disease-related
 - Mortality (dead-alive)
 - Morbidity (Infection: severe, mild-moderated, absent)
 - Health related
 - Somatic growth (4 patterns)
 - Psychomotor (Griffits score)
 - Neuromotor (Normal-abnormal)
 - Head perimeter (normal abnormal)
 - Breast feeding up to 3 months (appropriate, inappropriate)

Multi-attribute utility function



- Additive multi-attribute function:
 - Each attribute represents one dimension (e.g. somatic growth is one dimension)
 - The multi-attribute utility for an individual is the weighted average of each uni-dimensional utility
 - Weights for each dimension assigned by experts consensus (Swinging weights method)
 - Preferences (scores) for each outcome in each dimension

Multi-attribute utility function



$$V_i^x < \left[\begin{aligned} &w_{IC} u_{IC}(x_{ICi}) + w_{SI} u_{SI}(x_{SIi}) \\ &+ w_{DP} u_{DP}(x_{DPI}) \\ &+ w_{DN} u_{DN}(x_{DNI}) + w_{LM} u_{LM}(x_{LMI}) \\ &+ w_{PC} u_{PC}(x_{PCi}) \end{aligned} \right]$$

Direct scoring of discrete health states



- Experts rank by consensus the outcome variables:
 - Disease-related
 - Mortality
 - Infection: severe, mild-moderated, absent)
 - Health related
 - Somatic growth (4 patterns)
 - Psychomotor (Griffits score)
 - Neuromotor (Normal-abnormal)
 - Head perimeter (normal abnormal)
 - Breast feeding up to 3 months (appropriate, inappropriate)

Direct scoring of discrete health states



- All covariance patterns (taking into account the assigned ranks) of outcomes are listed, and reduced to significant discrete health states
- Anchor states (“perfect” health 1, death or worse than dead, 0)
- Scoring of states by experts (upwards and downwards)
- Nominal group consensus technique

Número del Estado	Desarrollo Psicomotor - Griffiths	Desarrollo Neuromotor - INFANIB	Perímetro Cefálico	Índice de Crecimiento	Lactancia Materna	Frecuencia y Severidad de la Infección
1	Satisfactorio	Normal	Superior -2σ	Normal	Adecuada	Sin Infección - Leve
2	Satisfactorio	Normal	Superior -2σ	Normal	Adecuada	Severa
2	Satisfactorio	Normal	Superior -2σ	Normal	Inadecuada	Sin Infección - Leve
3	Satisfactorio	Normal	Superior -2σ	Normal	Inadecuada	Severa
3	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Sin Infección - Leve
3	Satisfactorio	Normal	Superior -2σ	Anormal	Inadecuada	Sin Infección - Leve
3	Satisfactorio	Normal	Superior -2σ	Anormal	Inadecuada	Severa
4	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Infección - Leve
4	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Infección - Leve
5	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Infección - Leve
5	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Infección - Leve
5	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Severa
6	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Infección - Leve
6	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Sin Infección
6	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Infección - Leve
6	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Infección - Leve
6	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Sin Infección
7	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Severa
7	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Sin Infección
7	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Severa
7	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Severa
7	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Sin Infección
7	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Leve
7	Satisfactorio	Normal	Superior -2σ	Anormal	Adecuada	Sin Infección
8	No_Satisfactorio	No_Normal	Superior -2σ	Normal	Adecuada	Sin Infección
8	No_Satisfactorio	No_Normal	Superior -2σ	Normal	Inadecuada	Sin Infección - Leve
8	No_Satisfactorio	No_Normal	Superior -2σ	Anormal	Inadecuada	Sin Infección
9	No_Satisfactorio	No_Normal	Superior -2σ	Anormal	Adecuada	Severa
9	No_Satisfactorio	No_Normal	Inferior -2σ	Normal	Adecuada	Sin Infección - Leve
9	No_Satisfactorio	No_Normal	Inferior -2σ	Normal	Inadecuada	Sin Infección
9	No_Satisfactorio	No_Normal	Inferior -2σ	Anormal	Adecuada	Severa
10	No_Satisfactorio	No_Normal	Inferior -2σ	Anormal	Inadecuada	Severa
10	Fallecidos					

Ten, mutually exclusive discrete health states

Infants classified according to objective measurements

Summarizes KMC-related health status at 1 year of age

Each status is associated with a utility score



CONCLUSIONS



Conclusions

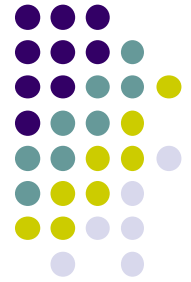
- First reported instrument to quantify HRQOL (utilities) in KMC preterm infants
- Based on measured outcomes, not on reported attributes
- Scoring (utilities) attempt to quantify relative HRQOL
- One important domain not yet included: wellbeing related outcomes (need for population-based reference standards)

Conclusions – Implications for practice



- Health Status inventory and utilities can be used in current KMC programs
 - For quality assessment-improvement
 - Benchmarking
- Not an instrument for communicating prognosis to parents

Conclusions – Implications for practice



- Useful for clinical and epidemiological research (provide utility weights for computing quality-adjusted life years' equivalents, and/or QALYs)

Conclusions – Implications for Research



- Need for incorporating items from the infant-family wellbeing domain
 - Simplified and validated instruments for
 - Mother feelings, stress and coping mechanisms – mood (depression, burnout)
 - Family adjustment – satisfaction and feeling of competence with parental role
 - Mother-infant bonding and attachment
 - Home physical environment

Conclusions – Implications for Research



- Future research
 - Construct validation
 - Elicitation of parents preferences to calibrate utility scores
 - Psychometric properties assessment

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Thanks

