Perceptions of Family Members and Healthcare Professionals on the Quality of Dying and Death in ICU of Hong Kong

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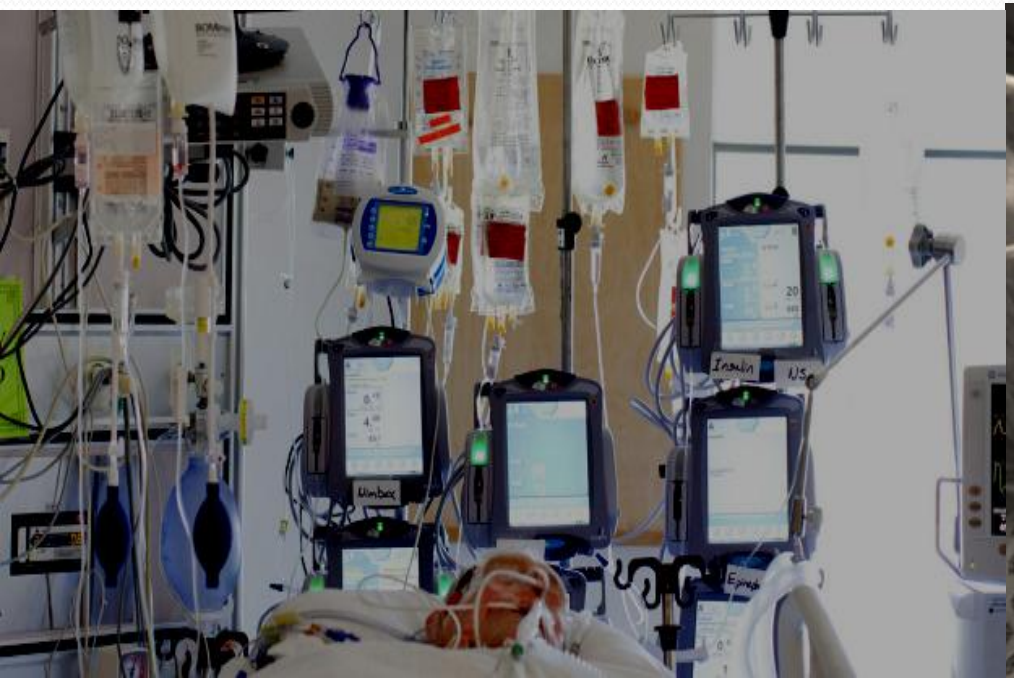


- Background
- Objectives
- Method
  - Study design
  - Instrument
  - Data collection
- Result & Discussion
- Recommendations
- Conclusion

Background

- ICU is a common location where healthcare professionals make the transition from attempting to cure disease and prolong life to provide comfort and death with dignity

(Curtis & Rubenfeld, 2001)

- Patients' conditions are complex and death maybe unexpected during the care trajectory, make managing death more difficult

Background

- "**Good Death**" identified as a major goal in improving quality of care for dying patient (Beckstrand, Callister & Kirchhoff, 2006)

- In order to achieve a good death, we have to understand the quality of ***dying experiences*** and ***factors*** affect the quality of dying and death

- No study was conducted to explore the quality of dying in Chinese population

Objectives

- To examine the quality of dying of ICU patients from nurses' perception
- To examine the quality of dying of ICU patients from family members' perception
- To compare the perceptions of nurses and family members on the quality of dying of ICU patients
- To identify items that are related to higher quality rating of dying of ICU patients from the perceptions of family members

Method-
Study design and setting

- Cross-sectional survey of nurses and family members of patients who died during a stay in adult ICU of Queen Elizabeth Hospital

Instrument

- Quality of Dying and Death Questionnaire (QODD)

(University of Washington, 2002)

- quantitative measurement completed by family members or healthcare professionals after patients' death to evaluate the decedent's experience at the end of life

(Curtis & Engelberg, 2006)

- 2 versions :

  ICU QODD-family member

  ICU QODD-healthcare professional

Instrument

- ICU QODD -Family member

-total 22 items

- *first part* :the frequency of symptom (such as pain) and dying experience (such as maintaining personal dignity)

- *second part:* to rate how particular symptom or experience affect the quality of dying

1a. How often did your loved one appear to have his/her pain under control?
(Circle one number)

0	None of the time
1	A little bit of the time
2	Some of the time
3	A good bit of the time
4	Most of the time
5	All of the time
6	Don't know >>>>>>>>>> *Go to Question 2a.*

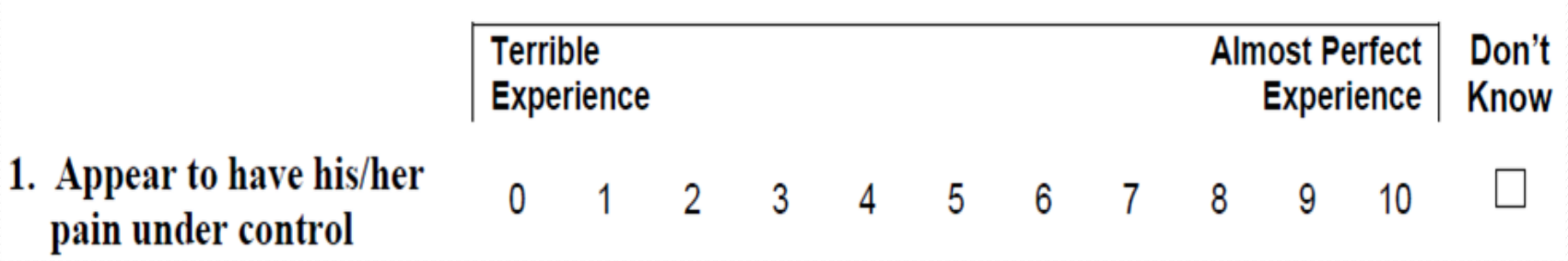
b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect

Instrument

- ICU QODD - Healthcare professional

- contain only the *second part*(quality)of ICU QODD-family member: rate how the symptom or experience of the patient affect the quality of dying



	Terrible Experience										Almost Perfect Experience	Don't Know
1. Appear to have his/her pain under control	0	1	2	3	4	5	6	7	8	9	10	☐

Conceptual Domain Under the ICU QODD

- Symptoms and personal care
  - Having pain under control
  - Having control of events
  - Being able to feed oneself
  - Being able to breath comfortably
- Preparation for death
  - Feel at peace with dying
  - Be unafraid of dying
  - Have health-care costs provided
  - Visits from religious/spiritual advisor
  - Have a spiritual service or ceremony
  - Have funeral arrangements in order
  - Say goodbye to loved ones
  - Clear up bad feelings
- Family concerns
  - Spending time with family/friends
  - Spending time alone
- Treatment preferences
  - Discuss wishes for end-of-life care
  - Being on ventilator
  - Being on dialysis
- Whole-person concerns
  - Finding meaning and purpose
  - Being touched and hugged by loved ones
  - Being able to laugh and smile
  - Keeping one's dignity and self-respect
- Moment of death
  - State at moment of death
  - Having family present at moment of death

Data Collection

- 3 data set for each identified death

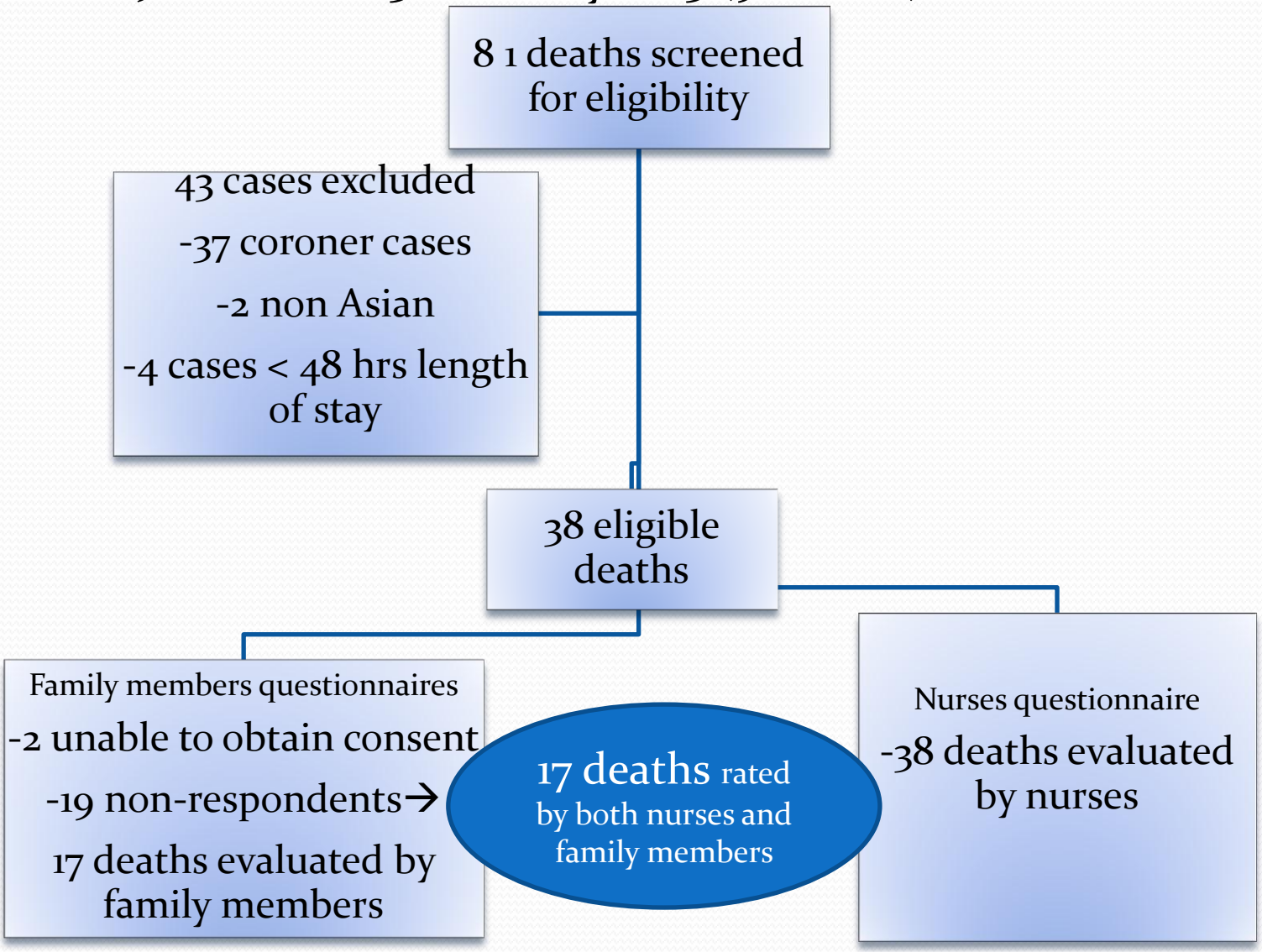
Patients demographic data as abstracted from the medical record

Demographic data & Self-administered ICU QODD-Healthcare professional

Demographic data & Self-administered ICU QODD-Family member

Data Collection

From 1st June, 2012 to 31 February, 2013 (9months)



Result

Perception of nurses and family members

Patients demographic data

Characteristics (N=17)	Data
Mean age of death (SD)	71(13) years
Male gender(N)	59% (10)
Mean length of stay in ICU (SD)	1 5(14) days
Primary system failure:	
Cardiac(N)	12%(2)
Respiratory(N)	40%(7)
Neurology(N)	12%(2)
Gastrointestinal(N)	24%(4)
Rheumatology/Haematology(N)	6%(1)
Renal(N)	6% (1)

End of life decision:	
CPR(N)	6%(1)
DNR(N)	76%(13)
Withdrawal of therapy(N)	6%(1)
Withhold of therapy(N)	12%(2)

Nurses demographic data

Characteristic (N=34)	Data
Mean age-years old (SD)	35(5)
Male gender (N)	26% (9)
With religious belief	0%
Education level:	
Associated Degree (N)	9% (3)
Bachelor (N)	59%(20)
Master (N)	32% (11)
Mean ICU working experience –years (SD)	7.5 (4)
With previous end of life training	0%

Family members demographic data

Characteristic (n=17)	
Mean age-years (SD)	45.4(10.7)
Male, gender(N)	23.5%($)
Religious believe, Yes(N)	35.3% (5)
Education level:	
Primary school (N)	5.9%(1)
Secondary school(N)	41.2%(7)
High diploma(N)	11.8% (2)
University(N)	35.3%(6)
Master(N)	5.9%(1)

Relation with patient:	
Spouse(N)	5.9%(1)
Children(N)	58.8% (10)
Sibling(N)	11.8%(2)
Parents(N)	5.9%(1)
Others(N)	17.6%(3)
Live with patient, Yes(N)	29.4%(5)
Mean year of knowing patient (SD)	39.1(10.3)

Mean scores of each item and the mean total ICU QODD score of different raters (17 deaths)

Questions/items	Family members(SD)	Nurses(SD)	*p* value* (p<0.05 as statistical significant) *Wilcoxon rank-sum test
Had control of pain	5.7(2.9)	6.4(1.1)	0.366
Had control of event	4.6(2.9)	4.5(2.1)	0.609
Breath comfortably	4.6(2.8)	6.1(1.6)	0.077
Felt at peace with dying	4.3(3.1)	5.7(2.0)	0.206
Unafraid of dying	5.0(3.0)	5.4(2.2)	0.674
Had visit from religious/spiritual advisor	5.9(2.1)	2.7(2.8)	0.007
Had a spiritual service or ceremony before death	5.1(2.3)	3.1(2.5)	0.181
Said goodbye to loved ones	3.8(2.7)	2.5(2.1)	0.395
Cleared up bad feeling	5.0(2.9)	3.7(2.5)	0.461

Questions/items	Family members (SD)	Nurses (SD)	*p* value* (p<0.05 as statistical significant)
Spent time with family/friends	6.4(2.9)	7.0(1.4)	0.370
Discussed wishes for end of life care with doctor	3.6(2.8)	3.5(2.4)	0.916
Being on ventilator	4.7(3.4)	5.9(1.9)	0.163
Being on dialysis	4.1(2.9)	4.2(1.5)	0.954
Being touched and hugged by loved one	7.2(1.8)	6.7(1.3)	0.396
Being able to smile/laugh	3.3(2.3)	1.8 (1.2)	0.211
Maintained dignity and self-respect	5.9(2.5)	5.4(2.6)	0.795
State at the moment of death	4.4(2.7)	6.7(1.7)	0.031
Had family present at moment of death	7.6(2.7)	7.0(2.1)	0.448

	Family members (SD)	Nurses(SD)	*p* value* (p<0.05 as statistical significant)
Mean total ICUQODD score	5.2(1.9)	5.2(1.5)	0.756

Highest and lowest quality rating items

Highest rating (family members)	**Highest rating (nurses)**
1. Having family present	1. Having family present
2. Being hugged and touched	2.Spending time with family
3. Spending time with family	3. Being hugged and touched

Lowest rating(family member)	**Lowest rating (nurses)**
1. Being able to smile/laugh	*1. Having visit from religious/ spiritual advisor*
2. Saying goodbye to loved one	2. Being able to smile/laugh
3. Discussing wish for end of life care	3. Saying goodbye to loved one

Discussion

Perceptions of nurses and family members

Comparison of quality of dying and death with prior studies

Paper authors	Setting	Mean ICU QODD-family member score	Mean ICU QODD-healthcare professional score
Hodde et al. (2004)	US hospital ICU	----	73.1
Mularski et al. (2004)	US hospital ICU	60	-----
Treece et al. (2004)	US hospital ICU	----	78.3
Mularski et al. (2005)	US hospital ICU	60	-----
Levy et la. (2005)	US hospital ICU	77.7	66.9
Glaven et al. (2008)	US hospital ICU	61.8	-----
Curtis et al, (2008)	US hospital ICU	62.3	-----
Gerritsen et al, (2013)	Netherlands ICU	85	80
Study (2013)	Hong Kong ICU	52	52

Comparison of quality of dying and death with prior studies

Lowest quality of dying and death

- Difference in cultural and clinical setting in ICUs
- Chinese tends to be stringent in rating

Comparison of family members' and nurses' perception on the quality of dying and death

- Nurses consistently reported lower score than family

(Hodde, Engelberg & Treece et al., 2004, Curtis, Nielsen & Treece etal., 2011)

➢ Social and professional role of the respondents

In current study:

- Family members rated 11 items higher than nurses

- No significant difference in the overall QODD mean score between nurses and family members: total QODD ~ 52/100

➢ Small sample size

Lowest quality rating items

- >70% of family members rated: **absent of saying goodbye to loved one** and **patient rarely smile or laugh**
  - Patients were intubated and comatose at the moment of death

- >80% family members rated: the **absence of end of life wishes discussion**

➢ Talking about dying and death is a taboo in Chinese population

➢ The coexistence of Chinese and western culture in HK, where the western culture values individual rights and self-determination.

(Ip, Gilligan & Koenig et.al , 1998)

- >70% of family members rated: the **absence of religious/spiritual advisor visit**
- No documentation of religious/spiritual support

Result

Items related to higher ICU QODD

Items associated with higher ICU QODD-family member score

Questions /items (continuous variables)	**Correlation coefficient (r)**	***p* value** *p*<0.05 as statistical significant (2-tailed)
Had control of pain	0.514	0.035
Had control of event	0.208	0.424
Breath comfortably	0.514	0.035
Felt at peace with dying	0.111	0.671
Unafraid of dying	0.143	0.583
Being able to laugh and smile	0.141	0.589
Maintained dignity and self-respect	0.592	0.012
Spent time with family/friends	0.075	0.770

Questions /items (dichotomous variables)			*p* value p<0.05 as statistical significant (2-tailed)
Had consciousness at the moment of death	Yes No Don't know	0 17 0	----
Healthcare cost being taken care of	Yes No Don't know	16 0 1	----
Had funeral arrangement in order	Yes No Don't know	4 13 0	0.164
Had visits from religious/spiritual advisor	Yes No Don't know	4 11 1	0.433
Had a spiritual service or ceremony before death	Yes No Don't know	2 14 1	0.525
Said goodbye to loved ones	Yes No Don't know	3 12 2	1.000

Questions /items (dichotomous variables)			*p* value p<0.05 as statistical significant (2-tailed)
Cleared up bad feelings	Yes No Don't know	3 6 8	0.071
Had family present at moment of death	Yes No Don't know	15 2 0	0.766
Discussed wishes for end-of life care	Yes No Don't know	2 13 2	0.027
Being on ventilator	Yes No Don't know	16 1 0	0.102
Being on dialysis	Yes No Don't know	15 2 0	0.551
Being touched and hugged by love ones	Yes No Don't know	14 3 0	0.378

Discussion

Items related to higher quality of dying and death

- **Physical symptoms management**

- Symptom management was shown as most important for a good death (Chan,2004)
- Pain is a stressor during a stay in ICU (Granja, Lopes & Moreira,2005)
- 47% of family members rated: pain under control most or all of the time
- No documentation of assessment or titration of medication for pain relieve
- Sedation mask the painful expression of the patient→ difficult to assess

- Only 24% of family rated : patient breath comfortably most of the time
- Family maybe overwhelm by the procedure and equipment in ICU
- Nurses play an important role in providing bedside ***communication*** with family member to provide appropriate information and reassurance
- ***Early identification and management***

- **Maintaining dignity and self-respect**

- Commonly rated as important in ICU studies
- 40% of family members rated: maintaining dignity and self-respect most or all of the time
- ***Provide general hygiene care, enhance comfort ,maintaining privacy, a clean and silent environment***
- ***Patient and family-centered care***

- **Discussion of end of life care wishes**

- Regular discussion about care strategies and patients' wishes were considered in the overall care plan →improve family's satisfaction in end of life care

  (Gries, Curtis & Wall, 2008)

- Communication skill– an important component of a high quality of the discussion (Troug, Campbell & Curtis etal., 2008)

- Fewer adverse events and better outcome

  (Emanuel, Taylor , Hain etal., 2011)

- No nurses had previous end of life care / communication training

Recommendations

Recommendations

1. Patient and/ family centered care

- Important in showing respect to patient and family members (Curtis,2004)
- Delivery information in a way that are sensitive to patients' cultural, religious, and language needs when making decision
- Identification of decision maker
- Identification of patient's living wills

2. Enhance communication

- An information leaflet delivered at the family first visit can improve the effectiveness of information impart to family

  (Azoulay, Pochard & Chevret, 2002)

- Information leaflet: visiting guideline, the common device used, terms commonly used in ICU etc

- Regular and open communication
- Build up a rapport
- Value the family input and support the family

- Family meeting : patient diagnosis and prognosis, goal of treatment, the needs of patient/family, family's understanding

- Communication training
- Education of the end of life care issue

3. Pain management

- Early identification and assessment
- Standardized assessment tool for mechanically ventilated patient in ICU
- Pain management guideline

4. Spiritual support

- Not just religious belief
- Understand patients/family wishes, belief, faith and values, ritual and practice
- Act as advocator
- Appropriate referral to other discipline e.g. social worker, bereavement service

Conclusion

- Moderate quality rating of dying and death of ICU patients
- No significant difference in the quality of dying and death between nurses and family members
- A **patient and family centered** end of life care is essential
- **Physical symptoms** were the most concerned in the quality of dying and death, assessment tool and management guideline are needed
- **Religious/spiritual support** by assessment and proper referral
- Maintaining **dignity and self-respect** of the patients
- **Adequate communication** between family and healthcare professional is important in end of life care

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Missing data

- Using observation with complete data only

  - listwise deletion: include cases in the analysis only id it has full data on all variables. (for large sample size, , missing data is small)

  - pairwise deletion: exclude cases only if they are missing the data required for the specific analysis

- Estimating missing data by imputation: using known relationship that can be identified in the valid values of the sample to help estimate the missing data

  -Mean replacement (it depresses the observed correlation that this variable will have with other variables because all missing data have a single constant value, this reducing variance

Instrument

- Total ICU QODD score:

  Sum of the quality rating (0-10)/no. of item completed x 10

- Higher ICU QODD score indicates higher quality of dying and death

- Case base approach for survey

  - author suggestion and decide

  - all the past studies used the same method→ comparison with the past studies

  - demographic data of the patient may have effect of the quality eg age, disease(ICH, trauma→unconscious, little or no pain)

- > 48 hrs of LOS

- to max. the probability all family or nurses to observe the pt's dying experience in ICU

- Average of nurse

-provide care at the last 12 hours, as dying process in ICU patient may vary from day to hours. To ensure at least one complete shift of care and dying experience was observed.

QODD

- Quality of dying and death is multidimensional and subjective

-> multi items measure

-> weighting of item based on patient preferences

->case based, the dying experience individualized

→Meaningful picture of the quality of dying and death

- Reported reliability and validity
- Only a/v for ICU setting

Chronbach alpha

- Internal consistency, reflect extent to which items measure the same characteristic
- A)Multiple indicator as effects of a construct
- B)Multiple indicator as causes of a construct
- A) the indicator correlated
- B) not necessarily correlate(tapping quite different aspect that actually define the latent construct rather than emerge from it)
- → high internal consistency work against content validity, the extent to which a scale taps all aspect of construct. High internal consistency mean that only a portion of construct has been measure repeatedly, narrow in content

Correlation coeffieience

- 0.1-0.29 small
- 0.3-0.49 moderate
- 0.5-1.0 large

Background

Quality of dying and death:

-multidimensional and subjective in nature, with 7 board domains

1. physical experience
2. psychological experience
3. social experiences,
4. spiritual or existential experience
5. the nature of health care
6. life closure and death preparation
7. the circumstances of death.

(Hales, et.al, 2008)

Instrument-Psychometric Properties

- QODD

  - used for out-patient and hospice setting

  - internal consistency (Cronbach's alpha 0.86)

  (Patrick, Curtis & Engelberg et al, 2003)

  - Good cross-sectional construct validity, the QODD correlating significantly with measures of symptom burden, patient-clinician communication about treatment preferences, and several measures of quality of care ($p<0.01$)

  (Partick, Engleberg & Curtis, 2001)

- ICU QODD

  - modified from original QODD

  - choosing item from the original QODD relevant to death in ICU based on face validity

  - internal consistency (Cronbach's alpha 0.96)

  - moderate inter-rater reliability (intra class correlation coefficient 0.44)

  (Mularski, Curtis & Osborne et al, 2004, Hodde, Engelberg & Treece et al, 2004)

Implications

- Larger sample size with multi-healthcare professional (such as physician, nurse, physiotherapist) to further identify factors associated with higher quality of dying
- Agreement among after-death respondent
- Meaning of disagreement that exist among respondents
- Identify the accurate respond on the quality of dying and death

Method- Sampling

- Healthcare professionals

  - All registered nurses who are currently working in ICU

- Nurses

  - 2 case-nurses who are involved in caring for patients during the last 12 hours before patient death

Method-Sampling

- Family members

  - 1 closest family member who familiarize the patient

  - who will be identified during the patient stay in ICU with the consensus from the family

Conceptual Domain Under the ICU QODD Instrument (Mularski. et.al. 2005)

- Symptoms and personal care
  - Having pain under control
  - Having control of events
  - Being able to feed oneself
  - Being able to breath comfortably
- Preparation for death
  - Feel at peace with dying
  - Be unafraid of dying
  - Have health-care costs provided
  - Visits from religious/spiritual advisor
  - Have a spiritual service or ceremony
  - Have funeral arrangements in order
  - Say goodbye to loved ones
  - Clear up bad feelings
- Family concerns
  - Spending time with family/friends
  - Spending time alone
- Treatment preferences
  - Discuss wishes for end-of-life care
  - Being on ventilator
  - Being on dialysis
- Whole-person concerns
  - Finding meaning and purpose
  - Being touched and hugged by loved ones
  - Being able to laugh and smile
  - Keeping one's dignity and self-respect
- Moment of death
  - State at moment of death
  - Having family present at moment of death

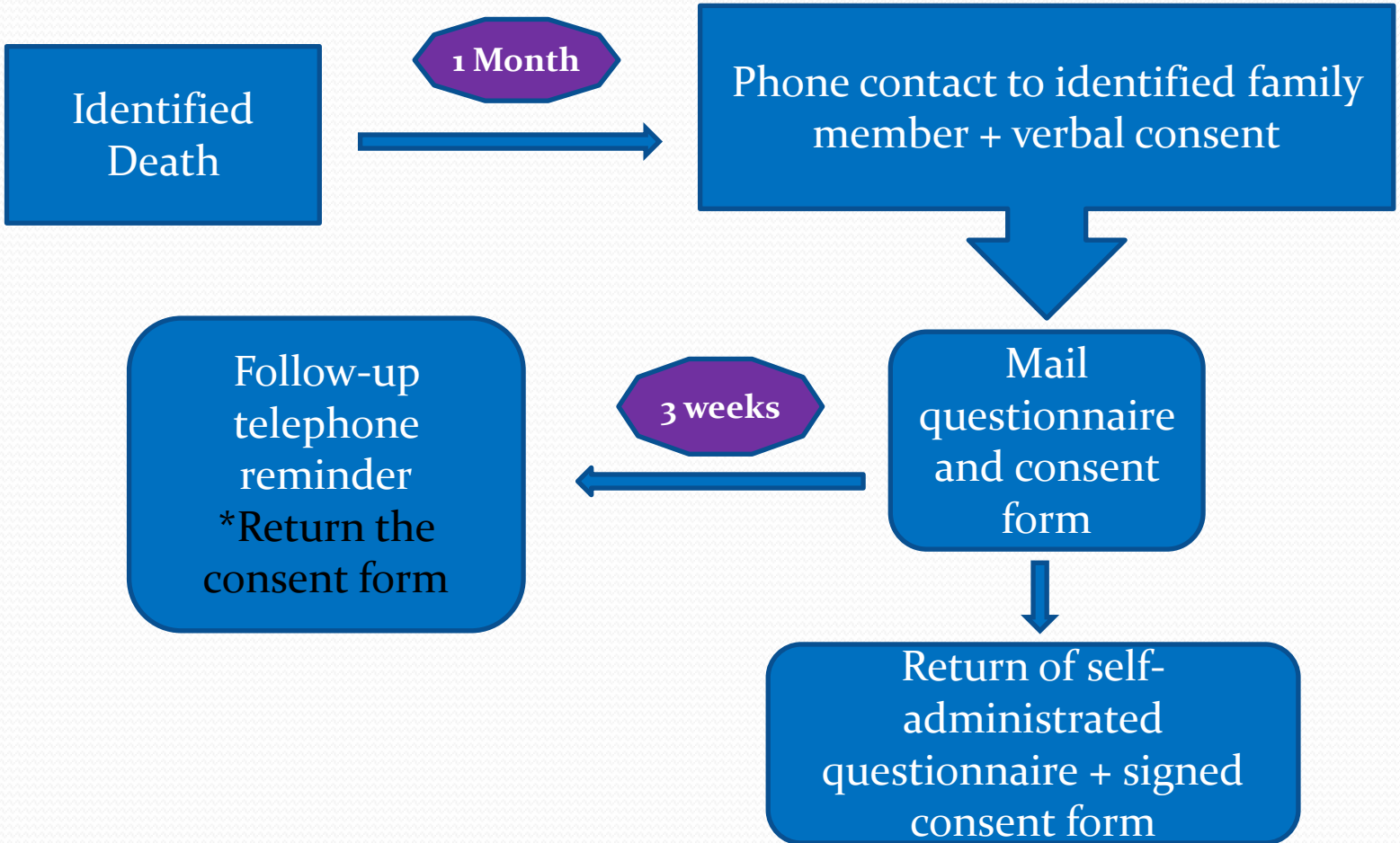
Data Collection

- Healthcare professionals

- Data from 2 nurses
- Within 48 hours after patient death
- E-mail to remind non-respondents 2 weeks later
- Score from the nurses were averaged as a total score of ICU QODD-healthcare professional of that patient

Data Collection

- Family members



Background

Definition

Quality of dying and death:

The quality of dying and death was defined as the degree to which a person's preferences for dying and the moment of death agree with observations of how the person actually died, as reported by others. (Patrick, Engelberg & Curtis, 2001)

Background

- Most ICU patients are unconscious and intubated → Family members and healthcare professionals are the best available information providers

(Hales, Zimmermann & Rodin, 2010)

Method- Subject

- A case based survey

  - length of stay >48 hrs before death

  - those deaths attribute to suicide, homicide or undergoing medical examiner review are excluded

- Healthcare professionals (nurses) and family members were recruited after identification of the cases

Instrument-Psychometric Properties

After the pilot study with 5 cases

ICU QODD-family member

- Internal consistency

Cronbach's alpha: 0.937

- Intraclass correlation(test-retest reliability): 0.98

Instrument-Psychometric Properties

- "**Content validity index**" was obtained by a panel of ICU professionals (2 nurse specialists, 2 Associate consultants).

- revisions were made and 2 questions about "whether the patient can feed themselves" and "how often the patient spend time alone "were eliminated as suggested (final version with 20 items in total)

- CVI = 1

- ICU QODD- healthcare professional

-CVI =1 (final version with 18 items in total)

Demographic Data

- Patient

  - gender, age of death, diagnosis during death, length of stay, end of life decision (i.e. DNR, CPR, withhold/ withdrawal of therapy)

- Family members

  -age, gender, religious believe, education level, relationship with patient, length of knowing the patient, level of burden of the questionnaire

- Healthcare professionals

  - age, gender, religious believe, education level, year of experience in ICU, any training in end of life topic

Highest quality rating items

- >80% of family members rated: the **family present at the moment of death** and **patient was being touched or hugged**; >60% of family members rated: **patient spending time with family at most of the time**
- Flexible visiting hour

Items associated with higher ICU QODD-healthcare professional score

Questions/items (dichotomous variables)	Occurrence of dying experience	N	*p* value (p<0.05 as statistical significant)
Had consciousness at the moment of death	Yes No Don't know	0 34 0	------
Had family present at moment of death	Yes No Don't know	32 2 0	0.769
Discussed wishes for end-of life care	Yes No Don't know	0 30 4	-------
Being on ventilator	Yes No Don't know	32 2 0	0.379
Being on dialysis	Yes No Don't know	32 2 0	0.241
Had right amount of sedation	Yes No Don't know	30 4 0	0.019
Kept alive too long	Yes No Don't know	8 24 2	0.486

Limitations

- Small sample size, also it is carried out in one ICU. It cannot be generalized into other ICUs
- The factor related to higher quality of dying and death cannot be identified due to small sample size
- Recall bias
- Non-respond rate is high (~50%)
- 2 missing items(unafraid of dying and clear up bad feeling)