

Cultural Considerations in Donation

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What is Culture?

- Maps of meaning through which the world is understood and interpreted
- Determines:
 1. Meaning of illness and death
 2. How decisions are controlled & made
 3. What role each family member plays
 4. How bad news should be communicated
 5. How grief & emotions are demonstrated
 6. What rituals/ceremonies are important

Culture in today's society

- Intra-cultural variability can be greater than inter-cultural variability
- Traditional cultural beliefs are likely to be modified by multi-cultural Canadian society
- Marriages involving different cultural backgrounds will also affect way cultures are expressed
- DO NOT ASSUME a person from a given background will automatically think a certain way

Importance of Culture in Donation

- Attitudes towards any decisions including whether to donate are influenced by culture
- Unspoken assumptions regarding meaning of health, illness and death may affect communication regarding donation
- National commitment to cultural pluralism and equality not always evident in prior experiences with the health care system

Ethics, Culture and Donation

- Respect for diversity = responsibility to respect peoples' differences and values
- Moral responsibility to respect cultural differences in how death and donation is understood, experienced and responded to

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Cultural Considerations

- No one has more or less culture another
- Culture determines notions of common sense
- Culture is passed from generation to generation without being articulated
- Cultural traditions affect us even if we do not participate in them
- The influence of culture in our lives may not be recognized

Culture and YOU

- Your religious/cultural perspective will influence your approach to organ donation
- Must understand your own values and beliefs before can try to understand someone else's
 - What is your cultural background?
 - What elements of this background do you express or believe?
 - How much does this background affect you in ways that you may not be conscious of?

Cultural Context

High Context (Non Western)

- Information drawn from context
- Group
- Interdependence
- Hierarchy
- Traditional ways
- Present time orientation

Low Context (Western)

- Information explicitly communicated
- Individual
- Autonomy
- Equality
- Question belief
- Future time orientation

Adapted from E. Hall, *Beyond Culture*

Locus of control

- Internal: determine own fate through actions
- External: events are determined by fate
- Western = internal
Non-Western = external

Practically Speaking

- Different cultures = different explanatory models of illness
- Different notions of self, of autonomy
- **Western** = biomedical basis of disease
- **Non-Western** = constant state of balance between health and illness
- May lead to major, unidentified discrepancies in perception of the illness, of importance of goals and of values

Problems in Quality Cross-Cultural EOL Care

- Marginalizing cultural & contextual information
- Secular focus
- Focus on autonomy
- Truth telling
- Negative focus

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**How to I address organ donation
with people from a different
cultural background?**

Culture and Organ Donation

- Have a spirit of inquiry and listen
- Be sensitive to non-verbal language
- Ask
 - How bad news is communicated
 - How decisions are made
 - How death/dying is discussed
 - How they think about organ and tissue donation
- Negotiate a communication plan

Some questions which might help....

- What do you think has caused your loved one's illness?
- How severe do you feel it is?
- What kind of treatment do you believe would work?
- Do you believe the timing of illness should be controlled and that the timing and nature of death can be influenced?

More Questions to ask..

- Do you value individual decision-making or are decisions made as a family?
- What personal/cultural beliefs do you hold about critical illness and death?
- How do they discuss issues such as death, dying?
- What personal/cultural beliefs does the family hold about organ and tissue donation?

How do I know if I am accommodating culture?

- Do I understand how the family perceives the cause and nature of this illness?
- Do I understand how the family perceives the nature and meaning of death?
- Do I understand how the family perceives organ donation?
- Are there any death related rituals or observances they wish to honour or perform?

How do I address organ and tissue donation with people from different religious backgrounds?

Religious Beliefs

- For some religious beliefs may directly influence whether notions of neurological death will be accepted or not.
- Some people feel need to consult with their religious leaders before making a decision regarding organ donation
- For some people may be important reason NOT to donate
- Religious leaders can be very helpful in facilitating discussions

Christianity

- Catholicism
 - encourage donation as an act of charity
- Protestantism
 - respects individual choice

INTACT BODY

- Some people believe intact bodies are needed in the next world
- Body is associated with soul or personhood of the deceased
 - Labeled “Mystical thinking” by some
- Some fear mutilation or disfigurement
 - Not purely on basis of religious reasons
- Ask: “ Can you tell me more about your concerns?”

ASIAN

- Reluctance to consent to transplant is due to notions of filial piety
- Filial Piety is basis of virtue and source of our teachings — *Hsiao Ching*
- Body is received from our parents
- In Confucianism dominates: Donation is the most unfilial act a person can perform
- Taoism: no objections to use of parts of body after death
- Debates centres on 'When is death?'
- Directed Donation to relatives first

Buddhism

- Donation is not widely practiced
- Range of opinions
- Conflicting definition of life and death
- Life is not permanent — no meaning to artificially extending it
- Person has own karmic destiny and life span
- Death is dissolution of mind and body — death of the mind is NOT death of the person

Buddhism

- Use cardiac death to define death
- Believe cutting the corpse or taking away organs pains the individual even after death
- Transplantation disrupts karmic destiny
- Only possible because someone else has died violates notion that one should never take a life
- Others feel since the body is transient, the gift of life is the greatest gift someone can give

JUDAISM

- In general saving a human life, *pikuah nefesh*, takes precedence over all other Laws
- Problem is determining when death has occurred
- Seven different positions on how to determine when death has occurred
- Range from requiring only an apnea test to brain liquefaction
- Most will want to consult Rabbi before making a decision re acceptance of neurological death and/or organ donation

ISLAM

- Source of much discussion
- Can donate organ in order to save a life or improve one's health
- Act of Piety
- Again concerns about defining death

When language is a barrier to communication....

Translator

- Warn of
 - Type of news you need to share
 - Expected substance of the conversation
 - The intensity of emotions
- Ask him/her if feels OK to proceed
- Emphasize need for confidentiality

Ground rules

- Set ground rules
 - Translate what I say and what they say in return
 - No embellishments or interpretations
 - Tell me what family says in response
 - If you have any questions about what I have told you, ask me BEFORE you translate to the family

How do I communicate via a Translator?

- KISC: Keep it simple & clear
- Pause after each piece of information
- Ask if the translator has any questions about what you have said BEFORE actual translation
- Make sure the conversation is not solely between you and the translator
- Ask what the family conveyed in response
- Ask translator to ask the family if they have any questions

Family member as translator

- Often the family member is placed in this position
- Awkward position to be in:
 - Intensely emotional time
 - Critical illness is often a concept NEVER imagined
 - Responsibility of translating
 - Acting as a “messenger”

How do I help the family member as translator?

- Ask them if they feel comfortable translating or if they would like you to find a professional
- Share with them the nature of the news you will be sharing
- Express concern regarding how difficult the role of translator can be at a time like this....
NORMALIZE and BE SUPPORTIVE
- Ask if there is anything you can do to make this role easier

How do I help the family member as translator?

- Negotiate a plan so that if it becomes too difficult a role to fulfill, they can stop
- Set ground rules...
- Ask that these rules be shared with the family
- Make sure the conversation does not occur SOLELY between you and the translator
- Be careful that the translator does NOT only selectively share information with the family
- Ask questions to check accuracy...

Difficult Provider

- May be a provider with
 - Poor communication skills
 - Poor collaboration skills
 - Misinformation/misconceptions
 - Personal beliefs regarding donation which will affect communication about donation
 - Different cultural/religious background
 - Different professional background
 - Difficult personality traits

WHAT did the MD say??

- Remember family acts as a filter
- May not reflect what the doctor said in the slightest!!!
- If in doubt or have questions, excuse yourself and ASK the MD
- BEFORE commenting/passing judgment make sure you know what the MD said

Tips for dealing with difficult provider

- Self –awareness:
 - Why do I find this person difficult?
 - How are our differences in values, beliefs, culture affecting our relationship?
 - How have I been contributing to the friction between us?
 - What role does the environment play?

Subverting Conflict

- How can you change your behaviour or make a conciliatory gesture?
- Avoid labels
 - e.g.: "ASSHOLE", or "IDIOT"
- Avoid matching anger and arguments
- Focus on the affective
- Try to understand the emotional meaning of conflict for both of you
 - Rejection of voice,
 - of professional standing,
 - of role

Skills for Conflict Resolution

- Create a climate of understanding
- Listen: what has caring for this patient meant for them?
- Be non-biased
- Encourage self- awareness — YOURS & THEIRS
- Stress the goals = to care for the patient/ to facilitate decision-making
NOT an “I WIN, YOU LOSE” situation

10 Steps to happiness

1. Negotiate the ground rules—
2. Forget the past
3. Identify the cost of conflict
4. Take the high road
5. Clarify what is really being said
6. Search for the meaning
7. Look for the affect
8. Find a shared purpose — patient's wishes
9. Test the choices for outcomes
10. Assess the larger picture/change the system

Practical Steps...

- Introduce yourself and express condolences
- Acknowledge how difficult the situation is for EVERYONE
 - This is a difficult situation for both of you....
- Acknowledge the strength and quality of the relationship with the ICU team
 - I can see how much you value Dr. Malloy....it is so nice that she is able to be here during this talk....
- Ask what is their sense of the goal of this meeting

Practical Steps

- Ask what they have discussed — if anything prior to your arrival...
- Offer your help in decision-making re donation
- Ask what they feel about organ donation after this earlier discussion with the ICU team
- Re-frame: “What I am hearing you say is....”
- “We all want to do what is best.... What would respect Emma”

If your credentials are questioned....

- DO NOT feel threatened
- Explain your background
- Explain your role:
 - I have sat with many other families in this tragic and difficult situation...
 - I would like the opportunity to help you as I have helped them
 - My help is in a focused way....

Mistakes

Can be retrieved:

1. by sharing your emotions
2. by apologizing
3. by backing up and explaining medical jargon



Always remember.....

- Life can change in a heartbeat
- It is a privilege to be a part of someone's life to hear the stories and share the sorrow — honor the experience
- The stories you will hear and the things you will see will teach you what is TRULY important in life
- It's a HARD road — sorrow and joy
- Bear Witness
- Learn.....

Conclusion

- Look, Listen & Learn
- Develop a consistent approach
- Practice
- Show you care
- Realize we all have & will continue to make mistakes and can always improve



Ethical, Moral and Legal Dilemmas

Resources

- TGLN standards to common dilemmas
- Ian Anderson Program:
www.cme.utoronto.ca/endoflife
- Joint Centre for Bioethics:
www.utoronto.ca/jcb
- Caring for Donor Families
- Cultural Issues in End-of-Life Decision Making
— Kathryn L. Braun (ed).
- Legal Advice — Hospital/TGLN