Advance Care Planning
Guidelines for working with Asian patients and their families

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PURPOSE

The purpose of this document is to provide information and guidance to clinicians to increase cultural awareness, sensitivity, knowledge and skills when working with Asian patients and their families.

DEMOGRAPHICS

The demography of the Auckland region is changing. Asian groups are now 22% of the region's population (SNZ, 2008). In 2010, around 310,000 Asian people resided in Auckland region, comprising 127,000 Chinese, 100,000 Indians and 84,000 Other Asian people. Asians was the second largest ethnic group in Auckland DHB, Waitemata DHB and across the Auckland region, and the third largest group in Counties Manukau DHB after European/Other and Pacific peoples (Mehta, 2012). One third of all Asian migrants had been in New Zealand fewer than 5 years.

WHO IS ASIAN?

'Asian' refers to people originating from countries in West Asia (Afghanistan and Nepal) South Asia (covering the Indian sub-continent), East Asia (covering China, North and South Korea, Taiwan, Hong Kong, Japan), and South East Asia (Singapore, Malaysia, the Philippines, Vietnam, Thailand, Myanmar, Laos and Kampuchea). This is the Statistics New Zealand Level One definition of Asian and is in common use within the health sector. Migrants refer to people who were born overseas who settle in New Zealand. 'Refugee' refers to people from a refugee background, who settled in New Zealand. Asian groups are diverse in culture, language, religion, education and migration experiences; however they do share certain collective cultural values and orientation. It is important to note that Asian patients may be from families who have lived in New Zealand for several generations.

THE NEED FOR CULTURALLY APPROPRIATE ADVANCE CARE PLANNING

- The provision of culturally appropriate advanced care planning involves clinicians eliciting and complying with the patient's preferences and values about disclosure, advance planning, and decision-making processes.
- The power imbalance in clinician-patient interactions may make it difficult for some Asian patients to directly request for culturally sensitive care (Hofstede, 2002). It is therefore important for health practitioners to improve their cultural awareness, sensitivity, knowledge and skill so that they can discuss disclosure, advance directives and advance care planning in ways that are understandable and are acceptable to Asian patients and their families.
- Clinicians need to offer autonomy to patients while respecting and acknowledging different cultural norms such as preferences for non-maleficience, non-disclosure and rights to independent decisions.
- Asian patients may prefer family-based decision making processes and refuse to make decisions in regard to their medical investigations or diagnostic procedures. In these cases patients must be provided with clear and voluntary choices
- Certain Asian cultures prefer to communicate information about serious illness and death subtlety instead of explicitly, by using facial expressions, voice tone, and other nonverbal cues
- It is important not to stereotype or make assumptions about an Asian patient's cultural beliefs, preferences and values, but always ask.
- If clinicians are able to learn and increase their awareness of the diverse Asian family values, spirituality, and relationship dynamics, they will gain trust and rapport with their Asian patients and their families.

GUIDELINES TO DEVELOP TRUST AND RAPPORT (CLINICIAN-PATIENT RELATIONSHIP)

The following should be considered:

- Showing an interest in the patient's cultural heritage.
- Knowing the *cultural affiliations* of your patients and what language and /or dialect they speak.
- Acknowledging the patient's status, in particular, for adult or elderly Asian patients by, addressing them using a formal title and surname.
- Understanding the patient's cultural orientation or level of acculturation.
- Understanding the definition of family (extended or nuclear) and relationships (marital, parent-child, sibling).
- Understanding how migration has impacted on the patient's family structure or system.
- Understanding the patient's attitudes toward advance directives, advance care planning and end-of-life care.
- Understanding religious and spiritual belief systems.
- Understanding views of suffering and afterlife.
- Understanding that there may be complex and sensitive cases where the views of an Asian patient's family members differ from clinicians about the obligation to prolong end of life care for their loved ones.
- Not assuming that the patient has an understanding of the New Zealand health and legal system and health professional roles.
- Consulting with families as well as individual patients, if family members are available.
- Exploring the locus of decision making.
- Exploring the patient's understanding of confidentiality.

GUIDELINES FOR DISCUSSING ADVANCED CARE PLANNING

The following should be considered:

- Understanding the patient's preference in relation to disclosure of diagnosis and prognosis
    - Autonomy (patients prefer to function independently).
    - Non-maleficence (the family prefers to protect the patient from the emotional and physical harm caused by direct communicating bad news and addressing death and end-of-life care).
    - Beneficence: (family prefers to encourage the patient's hope even in the face of terminal illness).
- Using specific scenarios to enhance understanding and reflection and to guide advance care planning. In the discussion, it is essential to explain to the patient the meaning behind medical jargon for example what a "do not resuscitate" order is.
- When explaining the risks and benefits of different treatment options, having a deeper discussion to explore the patient's values and preferences related to health and treatment in general and in specific situations.
- Using an interpreter if patients and /or family members do not understand English to explain advance directives, enduring powers-of-attorney and advance care planning.
- Providing translated information to the patients and/ or family members.

GUIDELINES TO IMPROVE COMMUNICATION

The following should be considered:

- Differences in communication patterns (direct versus indirect, nonverbal communication and gestures)
- Speaking clearly and slowly, avoiding jargon.
- Using open ended questions to avoid a "Yes" or a "No" answer.
- Checking for the patient's comprehension especially when requiring consent or decisions.
- Accessing a professionally trained interpreter to assist communication with limited or non-English speaking patients, instead of using a family member when dealing with sensitive issues that require understanding and consent from the patients/family members.
- Knowing how to work with interpreters effectively.

- Providing Advance Care Planning information to non-English speaking Asian patients and their families in their own language.

  Suggested questions to broach advance care planning
  - I'd like to talk to you about something I try to discuss with all of my patients. It's called advance care planning. Advanced care planning will help both of us to understand your values and preferences for health care if you become seriously ill.
  - Can you tell me about your current illness and how you are feeling?
  - Who would you trust to make decisions for you should you become mentally incapacitated?
  - What fears or worries, if any, do you have about the future?
  - In thinking about the future, have you thought about what is your preferred place of care as your illness gets worse?
  - What would give you the most comfort and meaning when your life draws to a close?

  Suggested approach to manage communication about serious illness and bad news:
  - Ask patients about the cultural issues that may affect communication of bad news and treatment *(before and <u>not after</u> the patients are sent for medical investigations).*
  - Ask patients if they would like to be directly informed of the results of medical investigations. (NB. Clinicians must let patients know that they are obligated to inform/discuss the patient's condition with the patient directly, unless they prefer otherwise).
  - Ask patients how they would like treatment decisions to be made. *(At this point, the clinician should determine the extent to which patients/family members wish to be involved in treatment decisions. If a patient prefers that family members receive information, find out which family member(s)).*
  - Ask patients and /or family members about their attitudes toward written advance directives, enduring powers-of attorney and advance care planning *(At this point, it is important to promote the importance of advance care planning and the benefits).*
  - Inform patients and/or family members about the availability of written advance directives, enduring powers-of-attorney and advance care planning information.
  - Ask the patient or family if there is a preferred approach for making decisions on the patient's behalf.

  NB: All this information should be documented in the patient's medical record

  Suggested approach to managing when family members are in conflict with medical views about what constitutes optimum qualify of life and end of life treatment or care
  - Ask about the views of family members and why, when further treatment is already futile, they need to comply with the wishes of the loved ones not to withdraw treatment or life support; or their reason(s) for not wanting to withdraw treatment or life support for the patient (when acting as the decision-maker).
  - Listen and hear their values and views respectfully.
  - Explain the medical view as to why stopping treatment or life support is in the best interests of the patient and explain what quality of life means (some Asian cultures value quantity of longevity more than quality of life).
  - Demonstrate awareness and understanding of their need to do their very best for their loved one; negotiate and balance the medical, legal and cultural views to help family members accept medical advice offered with empathy and compassion and to help them reduce their anguish about potentially not fulfilling their obligation to do the best for the patient from their perspective

GUIDELINES TO WORK WITH INTERPRETERS EFFECTIVELY

The following should be considered:

- **Before the session: Pre-brief interpreters**
  - Introduce yourself and your role.
  - Identify a leader for the session if more than one health professional is attending.

    - For face to face sessions, arrange an appropriate seating arrangement to facilitate the communication.
    - Brief interpreter on the purpose and objectives of the session.
    - Agree to use consecutive interpreting mode.
    - Brief all attendees on the confidentiality protocol (this also includes not discussing the patient in the session).
    - Obtain the cultural background from the interpreter if necessary, for example if you wish to understand cultural issues when disclosing bad news to the patient.
    - If needed ask the interpreter about the cultural context in which the patient is being given information and how best to give the information.

- **During the session (Briefing): Setting ground rules**
    - Introduce the interpreter and explain your role and the interpreter's role to the patient (include the fact that <u>everything said in the session will be interpreted</u> i.e. no private discussions between parties during the session).
    - Assure the patient that the rule of confidentiality applies to both the practitioner and the interpreter.
    - Establish ground rules for speaking *through* the interpreter (i.e. not *to*).
    - For face to face sessions, maintain eye contact with your patient (if appropriate) not with interpreter.
    - Expect the interpreter to use the 1st person singular when interpreting.
    - Direct the questions/statements to the patient or family, and not directly to the interpreter.
    - Do not enter into direct conversation with the interpreter.
    - Do not ask the interpreter for their opinion (except for cultural clarification).
    - Pause at regular intervals for the interpreter to assimilate and interpret.
    - Allow enough time for the interpreter to convey information (it may only take 3 words to explain but it may take more time for the interpreter to convey the information in their language).
    - Use short sentences

- **After the session (De-brief):** Clinicians can ask for a de-briefing to clarify any cultural issues, interpretation of words or concepts.

GUIDELINES FOR PROVIDING CULTURALLY SENSITIVE CARE

The following should be considered:

- Listening and observing.
- Not being judgemental.
- Not assuming.
- Not discriminating.
- Not stereotyping.
- Not being ethnocentric.
- Being careful when generalising.
- Having appropriate cultural attitudes.

COMPETENCIES

Clinicians need the following competencies to provide culturally appropriate Advance Care Planning for Asian patients and families:

- Be culturally competent working with Asian patients and families.
- Have an ability to develop rapport and trust with Asian patients and family members when broaching advance care planning.
- Have an ability to communicate effectively with Asian patients and their family members when broaching advance care planning.
- Have an ability to communicate information about serious illness and bad news appropriately.

- Have an ability to manage a situation when faced with conflict between family members and clinicians about the decision not to withdraw treatment and life support.
- Have an ability to assess if an interpreter is needed and to access and to work with interpreters effectively, when required.
- Have an ability to source and provide information to Asian patients and their families in their own language.

RESOURCES FOR HEALTH PRACTITIONERS WORKING IN THE AUCKLAND REGION

- For health practitioners employed by Waitemata DHB, Auckland DHB and Counties Manukau DHB, as well as primary health organisations and primary care organisations working in the area of advanced care planning, they can access the following accredited CALD cultural competency training which are available face to face or via e-learning (WDHB, Asian Health Support Services, 2010). Go to www.caldresources.org.nz
  - CALD 1: Culture and Cultural Competency
  - CALD 2: Working with Migrant Patients
  - CALD 3: Working with Refugee Patients
  - CALD 4: Working with Interpreters
  - CALD 7: Working with Religious Diversity
- For Auckland region clinicians: online cross-culture toolkits
  - Go to CALD Resources www.asianhealthservices.org.nz
  - Death and Dying Information from Different Asian Cultures and Religions www.caldresources.org.nz
  - See Appendix 1: Cultural perspectives and religious beliefs that influence the acceptance of advance care planning and the management of end of life care for Asian patients

- For Waitemata DHB clinicians: culture-specific resources available includes
  - Waitemata DHB Asian Patient Support Service www.asianhealthservices.org.nz
  - Waitemata DHB Interpreting Service: WATIS www.watis.org.nz

- For Auckland DHB clinicians: culture-specific resources available includes
  - Auckland District Health Board Interpreting Service
    Website: https://interpreters.adhb.govt.nz

- For Counties Manukau DHB clinicians: culture-specific resources available includes
  - Counties Manukau District Health Board Interpreting and Translation Service phip@cmdhb.org.nz

APPENDIX 1

CULTURAL PERSPECTIVES AND RELIGIOUS BELIEFS THAT INFLUENCE THE ACCEPTANCE OF ADVANCE CARE PLANNING AND THE MANAGEMENT OF END OF LIFE CARE FOR ASIAN PATIENTS

Clinicians need to understand the actual influence of culture on an Asian patient's value systems, attitudes and beliefs, and that we do not stereotype that all Asian patients as having the same worldview. Clinicians need to understand the degree of acculturation and the strength of ties with traditional beliefs when working with an Asian patient and their family members.

OVERVIEW

- Asian is not a heterogeneous group.
- Asian groups are very diverse in terms of cultural beliefs, customs, religious practices, education, acculturation level and social structures.
- Within each of the Asian sub groups, Asian Chinese and Asian Indian are heterogeneous in nature.
- In New Zealand, Chinese migrants mainly come from China, Hong Kong, Taiwan, Malaysia, Singapore, and Vietnam, whereas Indian migrants mainly come from India, South East Asian countries and Fiji.
- There is no typical Asian traditional family system.
- There are different customs and religious beliefs in Asian countries that influence death and funeral practices.
- There are different views, values and preferences when addressing end of life issues and serious illness
- One of the barriers cited by Asian patients is incompatibility of advance care planning with religious beliefs (Lip, 2009).

Chinese Perspective (Con, 2007; Htut, 2007; Lip, 2009; Tse, 2003)

- Advance directives, prolongation of life:
    - Advance directive is uncommon.
    - Have difficulty conceptualizing Advance Care Planning
    - Families would make every attempt to prevent someone from dying and may prefer a relative to stay in the hospital so that resuscitation is attempted at the last minute (usually because they do not want to feel guilty at not doing enough for the loved one during the end of life period)
- Quantity of longevity is more important than quality of life.
- Patient Autonomy: Physician and family-based decision making is preferred over patient autonomy
- Respect/Protection of Elders/Filial Piety:
    - May lead not to informing patients of illness to protect them, reluctance to place them in long-term care, reluctance to discuss Advance Directives
- Communication:
    - Disclosing diagnosis: often conveyed to family first, sensitivity and subtleness important because the family believes that the loved one may give up their will to live or may be upset and not be happy for the remaining period of the time.
    - Chinese who are deeply influenced by traditional Chinese culture, do not like discussing taboo subjects such as death, dying and cancer issues. They would prefer indirect nuances over truth telling. They believe that discussing death and dying may lead to something bad.
    - Some elders do not want to be a burden to their children. Medical professionals need to use care and be aware of their patient's beliefs in approaching these issues with Chinese elders or their families.
- Role of family in caring:
    - Family oriented.
    - Decision making is traditionally expected of the husband or oldest son.
    - Caring for the sick and dying is the duty of the family.
    - It is also important to ask about whether there is an accepted family decision-maker (Yeo, 1995).
- Home, hospice, or hospital
    - Home preferred, but hospice use can be encouraged.

- Post mortem and organ donation: Resistance toward organ donation may result from the concept of keeping the body whole for the afterlife, and out of respect. Attitudes can change depending on degree of acculturation.
- Philosophical teachings and their beliefs about death and after-life:
  - Confucian: `willing to die to preserve virtue': One should not be afraid of death. If a non-virtuous act is needed to preserve life, one would rather die.
  - Taoist: `life and death unified': Life and death are natural processes. One becomes part of nature upon death, and one needs not grieve when facing death.
  - Buddhist: `belief in new life after death': Death is part of the process of the wheel of rebirth. Death is a way to Nirvana.
  - Chinese traditional view about "a good ending" is that when facing death, the dying person feels comfortable, peaceful and surrounded by children/family.
- Religions of China and their beliefs about after life:
  - Islam - belief in after life and the day of judgment
  - Christianity - belief in resurrection.
  - For more Death and Dying Information – see resource booklet "Death and Dying Information from Different Asian Cultures and Religions" (WDHB, 2004).
- Decision Making Process and Family Determination: There are three level of preferences where
  - The family is happy to take part in decision making with the patient. This approach enables both the patient and the family to understand the bad news, and make decisions about further medical treatment or personal affairs together.
  - The patient asks the family to decide. The patient does not want the bad news, and the right for information and decision making is delegated to the family. For this approach, the patient is not told the bad news, but it is the result of the patient's own choice. This is also considered as exercising the patient's autonomy.
  - The family decides alone despite the patient's wish to participate. The patient wants to know the diagnosis, but the family do not want to let the patient know, hoping to protect the patient from potential harm. This is a more paternalistic approach and is common in a collectivist culture, where secrets are kept within subgroups of the family to protect the other family members from potentially painful knowledge.

Korean Perspective (Kim, 2004.5; Kim, 2012; Lee, 2012)

- Advance directives, prolongation of life:
  - Advance directive is uncommon.
  - Families would make every attempt to prevent someone from dying as part of filial piety and doing the best for the loved ones.
- Patient Autonomy:
  - Family-based medical decisions are a function of filial piety.
  - Illness is considered a family event, rather than an individual occurrence. (Searight, 2005)
- Role of family in caring:
  - Family oriented.
  - Decision makers traditionally expected to be the leader of family e.g. husband or oldest son—an orientation toward the extended family as opposed to individual patient self-interest.
  - Relationship between the parent and children is most important to Korean culture. The understanding is that a parent will make decisions for the best for their children and children will make decisions for the best for their parents to meet filial piety obligation, and this may conflict with practical decisions.
  - Parents and children may assume that they know what is best and not discuss the issue with each other. It is important for health professionals to understand why Koreans may not make clear decisions about advance care planning or end of life care, and why they often change their minds.
- Traditional and cultural beliefs about afterlife and funeral rituals
  - The afterlife is about separation of the soul (spirit) from the body. Once the soul is separated from the body after death, the soul will stay for a while in between the present world and the world of the dead. Funeral rites which take a few days help to make sure that the soul will start traveling to

the world of the dead safely without causing harm to the living or getting angry at the rest of family. As well, funeral rites allow the family time to say good bye. It is believed that the soul of dead person is taken by the messenger to the world of the dead. In modern society, the funeral rites will generally take up 3 days but can take up to 7 days.
  - Most Korean believes that death is not an end but a new beginning in the cycle of rebirth and that there will be a connection between the dead and the living. The dead person will be remembered and invited at the anniversary of the ancestor's death. A descendant will prepare the best food to serve to the dead, and there is a special ceremony called sacrificial rites. The family gets together to meet the dead person whom they consider to be still a part of the family. It is believed that well prepared funeral rites often guarantees wealth and health for the descendents.
  - Koreans celebrate the death of parents or grand parents if they have lived long and died in old age. This is called propitious mourning. A good death means parents' die before their children; that parents' die when their children are present; die without illness and; die after completing all parental responsibilities. It is important for health professionals to understand why Koreans may want to wait for children to arrive or come back from overseas to make decision such as removing ventilator in intensive care unit
  - Beliefs about life after death differ according to a person's age, religion, education and life experiences.
- The religions of Koreans and beliefs about the after life
  - Christians accept death because there is a positive outlook on death and the after life. Christian beliefs have been deeply influenced by Confucian thought, particularly of the neo-Confucian variety. There are also Buddhist and shamanistic influences in Korean Traditional Funeral Rites.
  - For more Death and Dying Information – see resource booklet about "Death and Dying Information from Different Asian Cultures and Religions" (WDHB, 2004).
- Decision Making Process and Family Determination:
  - Recent nursing research into preferences for advance directives in Korea revealed that many Korean people have an interest in advance directives (Kim, 2012). If there is no hope for recovery and death is imminent, most participants in the study did not want to receive cardiopulmonary resuscitation nor an IV or tube feeding. However, most wanted pain management care (Kim, 2012). The study showed that Koreans want to have family involvement or physician involvement for advance directives and want to verbally express their directives rather than use written documentation.
- There is a conflict between quality of life of dying person and filial piety of the children who are expected to do their best to support (both emotionally and financially) their loved one who is dying. Children will likely not want to make a decision about stopping the treatment if it is available and free.

Indian Perspective (Khanth, 2006)

- Advance directives, prolongation of life: Advance directive is uncommon; prolongation of life generally unacceptable
- Patient Autonomy: Physician and family-based decision making preferred over autonomy
- Communication:
  - Disclosing diagnosis – often conveyed to family first, sensitivity and subtleness important
  - Taboo words: death, dying, cancer; non verbal cues, indirect nuances preferred over truth telling
- Role of family in caring: Caring for the sick and dying is the duty of the family
- Home, hospice, or hospital
  - Home preferred, but hospice use can be encouraged
- Post mortem and organ donation: religious sentiments make these generally unacceptable unless necessary
- Religions of India and their beliefs about after life
  - Hinduism belief in karma and rebirth
  - Islam belief in after life and day of judgment
  - Christianity belief in resurrection
  - Buddhism belief in "eight fold path" for Moksha

- For more Death and Dying Information – see resource booklet about “Death and Dying Information from Different Asian Cultures and Religions” (WDHB, 2004)

Muslim Perspective (Con, 2007; Shah, 2012)

- Concept of health in Muslim culture is based on a holistic approach and wellbeing is seen as harmony in four interacting parts – Mind, Body, Soul and Spirit.
- Disease is defined as a disturbance in these four interacting parts, due to this concept of health member of Muslim community sometimes struggles to differentiate between physical and mental disorders.
- Family support is seen as integral to the process of recovery, if a family member is sick the whole family feels responsible to look after the one in need.
- Seeking any form of treatment is allowed whether traditional or western as long as it is recommended and legal form of treatment.
- Death is believed to have its set times for every human being and is expected to come at any time, therefore well accepted.
- Muslims believe in the afterlife and the Day of Judgment. They regard death as a transition from one phase of existence to the next
- It is preferred that Muslim people die at home. Care of the dying is a regular and essential responsibility of the immediate and extended family- which has historically been managed at home. With more young Muslims becoming professionals and moving away from their family homes, this is slowly eroding.
- Many families do not wish their dying relative to be informed of the prognosis. The aim of End-of-Life care is to reduce anxiety.
- Optimism and hope are regarded as some of the fruits of faith in Islam.
- Illness and disease is a test from Allah and illness should be received with patience, meditation and prayer.
- Palliative care services are valued and effective but people need to be informed that such services exist.
- For more Death and Dying Information – see resource booklet about “Death and Dying Information from Different Asian Cultures and Religions” (WDHB, 2004)

Sikhism and Hinduism (Con, 2007)

- Sikhism arose from Hinduism and these religions share a culture and world view that includes ideas of karma and rebirth; collective versus individual identity; a strong emphasis on purity and; a lifestyle based on ‘Ayurvedic’ medicine. These religions affect end-of-life decisions and care in a number of ways
- There is a perception that talking about death may make it occur and therefore the family are often reluctant to let their loved one know about their terminal illness.
- There is a preference to die at home or in a hospital but not in a palliative care units as the latter are seen as a place for dying people and may be seen as tainted.
- Withdrawal of food and water at the End-of-Life is not likely to occur because it is believed that both are needed for a good death.
- There may be a reluctance to use pain killers as pain must be endured (to help reach a higher state of mind).
- Withdrawal of treatment is acceptable if it is futile
- For more Death and Dying Information – see resource booklet about “Death and Dying Information from Different Asian Cultures and Religions” (WDHB, 2004)

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