

# CHALLENGES IN THE PROVISION OF END-OF-LIFE AND PALLIATIVE CARE TO ETHNIC NEPALI REFUGEES

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## Abstract

After over a decade of resettlement of ethnic Nepali refugees in the United States, there is a significant elderly refugee population that will require end-of-life care. The specific needs of ethnic Nepali refugees in the US were assessed in the 5 domains of (1) social and health inequities; (2) communication; (3) disclosure and decision-making locus; (4) spiritual and religious practice; (5) advance care planning and hospice. Social and health inequities in this population have created a specific burden of chronic respiratory disease. Multidisciplinary care and individualized care plans are the cornerstones of effective respiratory palliative care. The use of trained interpreters and cultural interpretation techniques can help overcome communication challenges in cross-cultural care. The Nepali population is heterogeneous in desire for illness disclosure and tend to favor family-centered decision making. Advance directives for disclosure can be considered to clarify the wishes of individual families. A respectful spiritual history and accommodation of end-of-life rituals is important to the end-of-life care of diverse populations. Nepali refugees are likely to be open to hospice and advance care planning if it is framed as supporting their ability to care for ill family members at home.

## Introduction

Since 2006 the United States of America (US) has resettled more than 85,000 refugees from Bhutan.<sup>1</sup> These families who have been resettled are primarily ethnic Nepali and Nepali speaking. In the 1980's the ruling Druk majority of Bhutan instituted a discriminatory "national identity movement" which mandated ethnic Nepali citizens conform with majority cultural practice, language and religion. Citizenship was stripped from many Nepali-speaking Bhutanese and through marginalization and intimidation the Druk majority in Bhutan expelled Nepali families en masse. By 1993 more than 100,000 ethnic Nepali were forced into resettlement in refugee camps located in southeast Nepal. After more than a decade of failed negotiations resettlement in third-countries began with the US accepting the majority of the refugees. The 3 most common sites of relocation in the US are Pennsylvania, Texas and New York. Virginia has

accepted the 9<sup>th</sup> highest number of ethnic Nepali refugees of US states, nearly 2000 between 2006 and 2012.<sup>2</sup>

Emigration to the US typically occurred in large family units which included elderly parents. In 2012, twenty percent of ethnic Nepali refugees in the US were between ages 45 and 64 years old. Five percent of the refugees were over the age of 65. Younger family members were generally responsible for the care of aging family members in the refugee camps.<sup>2</sup>

Palliative care techniques have been shown to improve quality of life, satisfaction with end-of-life care and in some cases mortality.<sup>3</sup> With the aging of the older members of the multigenerational Nepali refugee families, the need for providers of refugee care in the US to understand the tenets of palliative and end-of-care continues to grow. The WHO defines palliative care as follows:

*“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”<sup>4</sup>*

In 2014 the WHO initiated a global resolution on palliative care, seeking to improve access to palliative and end-of-life care across the globe.<sup>5,6</sup> This has spurred action which has expanded the availability of palliative medications and providers trained in end-of-life care for the native Nepali population (Paudel opioid availability and overview of PC papers).<sup>7,8</sup> This specialized care is unlikely to have been available to the elderly in refugee camps however.<sup>9</sup>

It is well recognized that end-of-life care varies across cultures and that challenges can arise in cross-cultural care in the US.<sup>10</sup> These data have been drawn primarily from non-refugee immigrants and there is very limited literature on palliative and end-of-life care in US refugees.<sup>9</sup> Kagawa-Singer & Blackhall<sup>10</sup> and Searight<sup>11</sup> both offer frameworks for the approach to cross-cultural end-of-life care. In this paper a synthesis of these approaches will be used to discuss the specific needs of Nepali refugees in the US at the end-of-life in 5 domains:

- 1) Social and health inequities
- 2) Communication
- 3) Disclosure and decision-making locus
- 4) Spiritual and religious practice
- 5) Advance care planning and hospice

### **Five domains of culturally competent end-of-life care**

#### *Social and health inequities*

The impact of social inequalities on tangible health outcomes is a fundamental aspect of the US healthcare system. Historical and persistent inequality in social determinants of health of African-Americans contributes to worse health outcomes<sup>12</sup> as well as different disease morphologies and perceptions of the healthcare

system<sup>10</sup>. Understanding and confronting those inequalities is key to appropriate end-of-life care for African-American patients.<sup>10</sup> Similarly, it is well known that refugees face unique patterns of disease as well as complex histories of discrimination, subjugation and trauma.<sup>11</sup> How the distinct experiences of ethnic Nepali refugees shape their health at the end of life must be understood by providers in order to be fully prepared to offer this population end-of-life care.

The medical conditions for which ethnic Nepali refugees in the US are requiring palliative care are not known. Several studies have assessed the palliative care needs of the native population of Nepal. The greatest projected need for palliative pain management in Nepal is cardiovascular disease. Chronic obstructive pulmonary disease (COPD) and cancer are projected to be tied as the second greatest need.<sup>13</sup> Chronic respiratory disease was identified as the most common reason (46%) for palliative care needs at an urban academic hospital in Nepal. Cardiovascular / cerebrovascular disease (23%), neurological disease (23%) and dementia/frailty syndrome (15%) were also identified as common reasons for palliative care need. Only 3% of patients with palliative care needs had cancer.<sup>14</sup> Similarly, the most common reason for palliative care needs at a rural Nepali hospital was COPD (78%) and no patients had palliative care needs due to cancer.<sup>15</sup> In-home assessment of palliative care needs in rural Nepal identified chronic respiratory disease as the primary driver of need (51.5%). In this setting dementia and frailty was the second most common driver of palliative care need (30.3%) and cancer represented 5% of palliative care need.<sup>16</sup> Nepali inpatients requiring palliative care were most likely to be suffering from fatigue and shortness of breath. Shortness of breath was twice as likely to be present and was rated to be more severe and functionally limiting than pain.<sup>14</sup> Nepali patients in the rural community were equally likely to be suffering severe pain and severe shortness of breath.<sup>16</sup> In the United States the primary drivers of palliative care need for all race-ethnicities are cancer and heart failure.<sup>17</sup>

The risk of chronic respiratory disease in ethnic Nepali refugees is uniquely rooted in the inequities of decades in refugee camps. Biomass fuel such as dung cakes, agricultural residue (straw, shrubbery and grass), coal-based fuels and kerosene are commonly used for cooking and indoor heating in Southeast Asia. Lung disease from biomass fuel exposure is a significant cause of morbidity throughout the region. Burning of these fuels indoors exposes families to carbon monoxide, polyaromatic hydrocarbons, formaldehyde and small solid particles. This indoor pollution is associated with COPD, lung cancer, asthma, pulmonary tuberculosis and interstitial lung disease (ILD) in adults.<sup>18</sup> In Nepali refugee camps women were frequently subjected to physical and sexual trauma when attempting to gather firewood for cooking and heating. In response to this UNHCR began to directly provide kerosene in the refugee camps.<sup>19</sup> Kerosene use for indoor heating and cooking in rural Nepal has been reported to have greater respiratory disease risk than other biomass fuels.<sup>20</sup> Furthermore, ethnic Nepali refugees have reported the belief that cooking outdoors is unclean.<sup>19</sup> The practice of indoor cooking with biofuels is not limited to ethnic Nepali refugees. In one study only 15% of rural Nepali households were found to cook in open air.<sup>20</sup> The respiratory risk is compounded by the energy saving tactic of building homes with deliberately poor ventilation in some rural areas of Nepal.<sup>21</sup>

COPD that is caused primarily by biofuels is not phenotypically identical to the tobacco-associated disease that is most common in the US. Biofuel-associated disease is less likely to be as responsive to exposure cessation as tobacco-associated disease is. The pattern of disease is also more likely to manifest with prominent airway disease and chronic bronchitis and less of an emphysematous phenotype.<sup>21</sup>

### *Communication*

The only consistent good level evidence in cross cultural-communication at the end of life is for the use of professional medical interpreters instead of family members.<sup>22</sup> In an Australian study assessing interpretation in Arabic,

Cantonese, Mandarin and Greek for oncology visits, family members acting as interpreters provided altered translations 50% of the time. Overall in that study 20% of non-equivalent interpretation negatively impacted the message conveyed, however 40% of non-equivalent interpretations were positive. Interpreters improved the physician's message in those cases by simplifying, clarifying or explaining in a culturally competent manner.<sup>23</sup> This is called cultural interpretation.<sup>22</sup> In the course of medical interpretation both family members and trained interpreters also speak to patients when not interpreting. This speech primarily serves a psychosocial or explanatory role. Family members are more likely to engage in this form of speech. They are also much more likely to intentionally mislead the patient as to the provider's message, however.<sup>23</sup> Preferences in communication style also vary cross-culturally. In Korea, Japan and China non-verbal communication is meant to subtly inform a patient of their illness even as the explicit verbal communication does not.<sup>10</sup> In Nepal healthcare workers endorse indirect discussion as the patients' and providers' preferred communication style for bad news. For example, asking a patient if they have any "wish [they] must complete" is preferred as a hint towards a poor prognosis.<sup>24</sup>

### *Disclosure and decision-making locus*

The concept of illness disclosure refers to a patient's preference for being told of the diagnosis of a terminal illness or stage of disease/prognosis. Cultural preference for non-disclosure is present in many Asian societies. Asian families commonly express the desire to spare the patient fear and worry which will risk worsening their condition.<sup>10</sup> This preference extends to a diverse variety of cultures. Non-disclosure is common practice in Portugal, Italy, Lebanon and the UAE.<sup>24</sup> Current preference for full disclosure in US oncology practice is a shift in practice which started in the 1970s. As recently as 2001, US oncologists reported providing truthful estimates of prognosis 37% of the time.<sup>25</sup> The application of western disclosure practices with a patient and family who are not

prepared for it may lead to distrust in the healthcare provider.<sup>10</sup> Inherent in the consideration of disclosure is discussing who will be responsible for a patient's decision making. Common US practice of patient-centered decision-making locus is contrasted with a family-centered decision-making locus which exists in many cultures. Hispanic Americans are often averse to appointing a single family member as a proxy decision maker as this is at odds with the culturally appropriate communal family-centered locus.<sup>11</sup>

Current Nepali oncology practice is most often to disclose to a patient's family and give the family the option to refuse disclosure to the patient.<sup>26</sup> Prognostication is usually only done with a patient's family members. Disclosure for diseases other than cancer is often withheld as well, though less frequently.<sup>24</sup> Midlevel healthcare providers of palliative care in rural Nepal have stated:

*"Our moral[ity] does not allow us to tell the patient he is dying soon. He has a right to live."<sup>24</sup>*

The right for a family to refuse disclosure to a patient is considered an "unchallengeable tenet of Nepali illness culture."<sup>26</sup>

In a survey of residents of a Nepali hospice, in which only cancer care is provided, 63% of patients were unaware of their diagnosis. Twenty percent knew both that they had cancer and the stage or relative prognosis of their disease. In a larger survey of the general Nepali population only 3% of respondents expressed the desire to have no knowledge of a cancer diagnosis if they were the patient, regardless of prognosis or stage. The vast majority of respondents (80%) would desire disclosure even if the disease was identified to be terminal or incurable. The remaining respondents desired disclosure only for curable disease. When provided with a hypothetical relative for whom disclosure was an option, a majority (60%) continued to support full disclosure in all circumstances. Fourteen percent did not want a relative informed at all.<sup>26</sup> While non-disclosure is clearly common in practice in Nepal, it is not

universal and personal preference in the healthy appears to favor disclosure. Whether or not disclosure occurs, Nepali society tends to favor family-centered decision making,<sup>2</sup> however little is known about the willingness of families to appoint unitary decision makers.

### *Spiritual and religious practice*

Patients' and families' perspectives on the end-of-life and the process of terminal illness are shaped by their religious and spiritual beliefs.<sup>10</sup> Attending to the spiritual and existential suffering of patients at the end of life is considered part of the ethical responsibilities of US physicians.<sup>27</sup> Ethnic Nepali refugees are majority Hindu (60%) and Buddhist (27%). An indigenous animistic religious belief system called Kirat is practiced by 10% of refugees from Nepal. There is also a small minority of Christian refugees (3%).<sup>2</sup>

In Hindu philosophy, death is a process through which the soul migrates to the next life or afterlife.<sup>28</sup> Dying is also typically seen as natural and cyclic<sup>29</sup> which leads to more support for non-aggressive end of life care.<sup>30</sup> The practice of ritual cremation near sacred bodies of water enables this process of migration. Modern palliative care and Hindu end-of-life practices have been integrated in Nepal through the establishment of end-of-life facilities on the grounds of an ashram (monastery) which receives sacred water from the Ganges River. Nepali hospices, including non-religious ones, often prominently display Hindu deities to provide comfort to patients. Two rituals which are thought to enable the passage of the soul to the next life include giving the patient water containing holy basil leaves (*tulsi*) and having the dying person hold the tail of a cow.<sup>28</sup> It is unclear how widespread and desired these rituals are by dying ethnic Nepali patients.

Buddhist philosophy is not uniform and there are many ethnic variations.<sup>29</sup> Similar to Hinduism, in Nepal Buddhists have a focus on the transmigration of soul at the end of life and dying is seen as a natural part of life.<sup>28</sup> Some believe in reincarnation and dying as a transition to the next life.<sup>29</sup> However, the site of death and specific rituals are not typically as prominent as

in Hindu belief. Palliative care access has been expanded in Nepal through the establishment of a hospice on the grounds of a monastery in a large Buddhist area of Nepal.<sup>28</sup> Buddhist tradition has heavily influenced multiple forms of Asian traditional medicine and many Buddhists apply these practices to medical illness.<sup>29</sup> The end-of-life philosophy of Buddhism as it is practiced in Nepal is focused on keeping the patient calm and un-fearful of death through psychological and spiritual care.<sup>28</sup> Buddhists generally oppose active euthanasia which is seen as inconsistent with their teaching to never harm or kill a living being. The same religious principle which drives Buddhist opposition to active euthanasia drives opposition to the concept of brain death. As brain death is required for many organ transplants to proceed, organ donation following brain death may be unacceptable for most Buddhists.<sup>29</sup> However, there appears to be significant support for a natural dying process and less aggressive end-of-life care.<sup>30</sup> How much and which of these principles apply to Nepali Buddhists in specific is unclear.

Influence from the majority Hindu and Buddhist surrounding culture over the last century has influenced Kirat belief systems significantly. There are unique Kirat death rituals which can include a priest-led dialogue with the soul of the deceased in an attempt to persuade them that their desires on earth have been fulfilled and they can ascend to heaven. In some cases, this ritual involves sacrifice of fowl. There is relatively little English-language scholarship on the Kirat faith with which to guide interactions with western healthcare systems and ethics.<sup>31</sup>

#### *Advance care planning and hospice*

Use of advance directives has proliferated in the US as they are viewed as a mechanism through which to preserve individual choice and autonomy in dire medical situations. The evidence has failed to show benefit for surrogate decision maker concordance with patient wishes, frequency of goals of care discussions, aggression of care at the end of life or cost of care.<sup>22</sup> Members of non-western cultures and

minority groups within the US frequently oppose the concept of explicit advance care planning.<sup>11</sup> Transitions to hospice care whether in a facility or at home make up a large part of US palliative care practice. In some Asian cultures, the tenet of filial piety contributes to reduced use of hospice services.<sup>10</sup>

While little is known about acceptability of advanced care planning in Nepal and for ethnic Nepali refugees, there appears to be widespread acceptability of hospice services and significant support from religious institutions as discussed previously.<sup>28</sup> Despite the expansion of hospice services, it is well documented that native Nepali patients are not aware of the difference in the mission of a hospice and that of a nursing home.<sup>26</sup> Elderly patients in rural Nepal often express the desire to return to their own land at the end of life rather than be stuck in an urban hospital and environment they are not comfortable with. Being in the presence of loved ones is considered of the utmost importance in death.<sup>24</sup>

#### **Discussion**

While the specific perspectives on end-of-life care of ethnic Nepali refugees in the US are not known, much can be learned from the general literature on cross-cultural end-of-life care and the attitudes and practices in the Nepali healthcare system. Each of the five domains discussed presents challenges in the care of ethnic Nepali refugees at the end of life. Table 1 presents those key challenges and recommendations for their approach in clinical practice.

#### *Palliation of chronic respiratory disease*

The interplay of the experiences of refugees in camps in rural Nepal, cultural beliefs about food preparation and rural home structure in Nepal has contributed to a significant burden of chronic respiratory disease. This social situation supports the evidence showing that in the Nepali healthcare system both urban and rural palliative care needs are most often for COPD. End-of-life symptom management for Nepalis is often more required for dyspnea and fatigue than pain. The underpinnings of the western

**Table 1:** Recommendations for the approach to challenges in the end-of-life care of ethnic Nepali refugees

Domain	Challenges	Recommendations
Social and health inequities	<ul style="list-style-type: none"> <li>- Palliation of chronic respiratory disease</li> </ul>	<ul style="list-style-type: none"> <li>- Empower families with individualized care plans</li> <li>- Consider home-based multidisciplinary models such as INSPIRED-COPD</li> <li>- Address nutrition in culturally appropriate manner</li> </ul>
Communication	<ul style="list-style-type: none"> <li>- Language barriers</li> <li>- Variation in preferred communication style</li> </ul>	<ul style="list-style-type: none"> <li>- Use of trained interpreters</li> <li>- Encourage cultural interpretation</li> <li>- Pre-brief and debrief with interpreter</li> </ul>
Disclosure and decision-making locus	<ul style="list-style-type: none"> <li>- Heterogenous desire for non-disclosure</li> <li>- Ethical concerns</li> <li>- Preference for family-centered decision making</li> </ul>	<ul style="list-style-type: none"> <li>- Consider advance directives for disclosure</li> <li>- Educate care providers on role of culture in ethics</li> <li>- Support communal decision-making processes</li> </ul>
Spiritual and religious practice	<ul style="list-style-type: none"> <li>- End-of-life rituals</li> <li>- Variable beliefs about end-of-life</li> </ul>	<ul style="list-style-type: none"> <li>- Obtain respectful spiritual history</li> <li>- Accommodate rituals as possible</li> <li>- Incorporate spiritual care providers in multidisciplinary teams</li> </ul>
Advance care planning and hospice	<ul style="list-style-type: none"> <li>- Possible reticence to engage in advance care planning and hospice</li> </ul>	<ul style="list-style-type: none"> <li>- Home-based care models</li> <li>- Emphasize role of hospice in supporting home-based care</li> </ul>

palliative care system were built for cancer care and pain management. The differences in distribution of disease for the Nepali, with very little cancer palliative care identified as a need is clearly different from the profile of palliative care needs in the US. It remains to be seen what the needs of refugees in the US will be and to what extent the differences in disease profile will shift towards that which is common in the US.

Western palliative care physicians have developed strategies for the palliation of respiratory disease.<sup>3</sup> The symptoms of deterioration in COPD are similar to those of lung disease, for which there is extensive palliative care literature. However, the morbidity and degradation in quality-of-life in COPD occurs over a much longer time scale which presents a unique challenge in provision of palliative care.<sup>32</sup> The traditional model of palliative care, built on the disease trajectory of most malignancies, is one of an abrupt and predictable decline. Organ failure, including

chronic respiratory disease, follows an entry-reentry trajectory with a gradual long-term decline which is punctuated by periods of exacerbation and recovery. Each recovery is to a level slightly lower than prior, but it is difficult to predict which exacerbation will not have a recovery.<sup>33</sup>

Primary palliative care can be provided by any provider, including primary care physicians, with the goal of alleviating their patients' suffering.<sup>34</sup> There are several key elements to the palliative management of COPD: advance care planning, management of dyspneic crises and nutrition.<sup>33,34</sup>

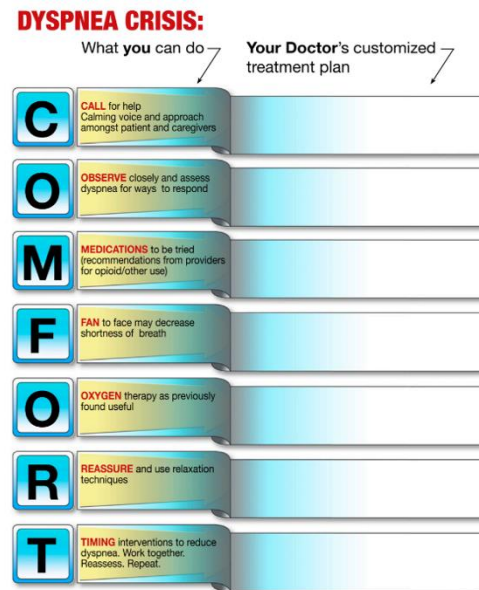
Though there is no evidence to guide the approach to advance care planning with ethnic Nepali refugees, there appears to be a clear and strong preference for death to occur at home with family. There also appears to be support in the major spiritual traditions of this group for de-escalation of end-of-life care and hospice. Given this, approaching discussions of hospice

under the framework of supporting the family in bringing the patient home may be a beneficial strategy.<sup>10</sup> Home based primary care models for elderly refugees in the UK are believed to improve communication and trust.<sup>35</sup> A home-based model for advance care planning may improve the quality of these discussions for ethnic Nepali refugees. Respectful and open exploration of a family's rituals and the limitations in the particular healthcare setting should be undertaken at the end of life. US hospitals are likely to be able to accommodate some rituals such as the display of iconography and the consumption of holy basil, however care at home will allow more flexibility in this regard. Working with families to properly observe their preferred end-of-life rituals can also enhance their trust in the physician and healthcare system.<sup>10</sup> Death at home for patients with COPD will require multidisciplinary care which includes respiratory therapists and spiritual care providers.<sup>34</sup>

In advanced COPD, dyspneic crises lead to cycles of emergency department visits and admissions followed by worsening functional status which impairs ability to manage worsening symptoms on return to home.<sup>36</sup> It is important to empower families caring for patients with advanced COPD to feel comfortable responding to worsening dyspnea at home. The general approach is graded therapy, starting with non-pharmacological steps such as pursed-lip breathing<sup>34</sup> and fans directed on the face<sup>37-39</sup> then progressing to inhaled bronchodilators and finally to opioids.<sup>34</sup> The American Thoracic Society has published a template for customized action plans called the COMFORT approach (Figure 1).<sup>40</sup> A similar approach was used in a Canadian program called INSPIRED-COPD, which used multidisciplinary support, in-home education, individualized written action plans for dyspneic crisis, and in-home advance care planning to reduce emergency department visits by 60% and COPD readmissions by 80%.<sup>36</sup> Effective implementation of such action plans will empower ethnic Nepali refugees to care for family members with chronic respiratory disease at home.

Inadequate nutrition is very common in advanced COPD as anorexia and dyspepsia are compounded by elevated resting energy expenditure. Nutritional supplementation has been shown to improve body weight and strength, improve airflow and improve quality of life.<sup>33</sup> The acceptability of US commercial nutritional supplements to elderly ethnic Nepali refugees is not known. Whether culturally acceptable alternatives for nutritional supplementation exist warrants further study.

**Figure 1:** American Thoracic Society schema for individualized caregiver action planning



### *Ethics of non-disclosure*

The ethical principle of autonomy centers the patient as the primary decision maker. This principle is the bedrock of the ethics of informed consent and is a product of the dominant European-American model of ethics. However, ethics is inextricable from the culture in which it is developed and applied. American medicine preferentially weights autonomy over beneficence, non-maleficence and justice. This is primarily a reflection of the core values of the dominant American culture and is rooted in the individualistic philosophy that guided early American government, history and jurisprudence. While American culture values

independence and protection of individual rights above all else, other cultures do not place the same relative weight on these principles.<sup>10</sup>

In cultures in which non-disclosure is preferred, the act of misleading a patient with a terminal illness in order to provide hope is an expression of the ethical principle of beneficence. Non-maleficence is being followed when families ask not to inform the patient in order to prevent the emotional and physical harm that would occur. Beneficence and non-maleficence are accepted principles in the US system of ethics. Non-disclosure often seems unethical from the perspective of American culture because it places the considerations of beneficence and non-maleficence over that of autonomy.<sup>11</sup> The legality of a patient providing consent for procedure or treatment while not being informed fully by choice is unclear.<sup>41</sup> The ethical underpinning exists however, as voluntarily putting aside one's autonomy is an expression of autonomy itself.<sup>11</sup> Physicians caring for ethnic Nepali refugees must work with their patients to understand their preferences and reach compromises between the ethical weighting system of the family and that of the physicians.

#### *Advance directives for disclosure*

Though there are no data addressing the disclosure preferences of ethnic Nepali refugees, the general cultural background of Nepal offers some guidance. The dominant practice in Nepal is non-disclosure, however the desire for disclosure is clearly heterogeneous. In other immigrant groups the desire for disclosure tends to change over the course of disease and with assimilation to US culture.<sup>22</sup> Cultures are not monoliths and assumptions about desire for disclosure in this population should not be made. This population appears more likely to favor non-disclosure than the general US population, however. Discussion of the disclosure preferences of refugee patients is thus recommended.

The appropriate timing and setting for such a discussion are not clear. One group has trialed an advance directive for disclosure in Japanese immigrants to the US on temporary work

assignment. They used a standardized questionnaire prior to any screening of diagnostic testing for cancer.<sup>42</sup> This questionnaire can be seen in Appendix A. There are clear limitations to this approach, as non-disclosure may be desired for non-cancer diagnoses and the handling of incidental cancer diagnoses would not be clarified by this approach.

In qualitative assessment of the survey it was found that most patients were supportive of this approach. Two of the patients in the study opposed the idea of having this discussion entirely, raising the concern that implementing this procedure would make a patient worry that the provider thinks they have cancer. There was also concern raised that expressing a desire for non-disclosure would impair the ability of the patient to trust that the physician is not hiding information from them at all visits.<sup>42</sup> Exploration of implementing Nepali language versions of an advance directive for disclosure with ethnic Nepali refugees may be beneficial. A modification of the form which addresses the above concerns, generalizes to any population and can be administered routinely outside the setting of screening or diagnostics is presented in Appendix B.

#### *Decision making at the end of life*

Ethnic Nepali refugees are likely to favor a family-centered decision-making process at the end of life. If this desire makes it difficult to appoint a unitary decision-maker at the end of life is not known. However, proxy decision making by committee has precedent in Virginia law. In the hierarchy of proxy medical decision-makers as laid out in the Virginia administrative code, any time there is a disagreement between multiple co-equal decision makers (such as multiple children of a patient) the final decision can be made by majority rule.<sup>43</sup> As such, if a unitary decision maker is not desired by a family, allowing the system to be more accepting of shared-responsibility spread across multiple family members may improve the experience of end-of-life planning and decision making.



### Communication style

Trained interpreters should always be used for end-of-life care discussion and advance care planning. This allows the clearest transfer of information to the patient, though there is clearly still a risk of misinterpretation. The need for interpretation significantly hampers the physician's ability to tailor their communication style to the patient's needs. The ability of family members serving as interpreters to provide this sort of psychosocial and non-verbal communication may be worthwhile in some scenarios. Employing trained interpreters using the "cultural interpretation" technique with explicit pre-brief and debrief about the visit is likely the best compromise to allow for culturally appropriate communication style and the most accurate interpretation possible.

### Limitations

There are significant limitations to drawing conclusions about ethnic Nepali refugees from the general culture of Nepal and similar South-East Asian countries as this information may not be applicable to this specific subgroup. The differences in the complex caste system of Nepal are also not well evaluated in the current literature.<sup>2</sup> The healthy migrant effect may result in a refugee population with significantly different perspectives than non-refugees as well.<sup>9</sup> There are no data collected from ethnic Nepali refugees within the US to help guide their care. As such, this is an area which warrants significant further investigation.

### Conclusion

Through analysis of five domains of cross-cultural end-of-life care, challenges in end-of-life care for ethnic Nepali refugees were identified. Recommendations for approaches to these challenges have been made. The goal of culturally competent care is to understand one's patient and to navigate the grey area between stereotyping based on someone's background and cultural imperialism in which providers' values are hoisted onto the patient. By respectfully exploring each individual patient and family's perspectives on these challenges, a culturally competent care plan can be produced.

### References

1. Bhutanese Refugees Find Home in America | whitehouse.gov. <https://obamawhitehouse.archives.gov/blog/2016/03/11/bhutanese-refugees-find-home-america>. Accessed June 23, 2019.
2. Bhutanese Refugee Health Profile | Bhutanese | Refugee Health Profiles | Immigrant and Refugee Health | CDC. <https://www.cdc.gov/immigrantrefugeehealth/profiles/bhutanese/index.html>. Published February 26, 2019. Accessed June 27, 2019.
3. Bowman B, Meier DE. Palliative care for respiratory disease: An education model of care. *Chron Respir Dis*. 2018;15(1):36-40. doi:10.1177/1479972317721562
4. WHO | WHO Definition of Palliative Care. <https://www.who.int/cancer/palliative/definition/en/>. Accessed June 23, 2019.
5. Connor SR, Sepulveda Bermedo MC, Worldwide Palliative Care Alliance, World Health Organization. *Global Atlas of Palliative Care at the End of Life.*; 2014.
6. Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. *The Lancet*. 2018;391(10128):1391-1454. doi:10.1016/S0140-6736(17)32513-8
7. Paudel BD, Dungal G, Munday D. Overview of Palliative Care. *Nepal J Obstet Gynaecol*. 2014;9(2):3-10. doi:10.3126/njog.v9i2.11724
8. Paudel BD, Ryan KM, Brown MS, et al. Opioid Availability and Palliative Care in Nepal: Influence of an International Pain Policy Fellowship. *J Pain Symptom Manage*. 2015;49(1):110-116. doi:10.1016/j.jpainsymman.2014.02.011
9. Madi F, Ismail H, Fouad FM, et al. Death, Dying, and End-of-Life Experiences Among Refugees: A Scoping Review. *J Palliat Care*. 2019;34(2):139-144. doi:10.1177/0825859718812770
10. Kagawa-Singer M, Blackhall LJ. Negotiating Cross-Cultural Issues at the End of Life: You Got to Go Where He Lives. *JAMA*. 2001;286(23):2993-3001. doi:10.1001/jama.286.23.2993
11. Searight HR. Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians. 2005;71(3):8.
12. Health disparities experienced by black or African Americans—United States. *MMWR Morb Mortal Wkly Rep*. 2005;54(1):1-3.
13. Swarbrick E, Pietroni MA, Munday D. The Need for Palliative Care in Adults in Nepal: Projections Based on Modeling Mortality Data. *Indian J Palliat Care*. 2019;25(1):41-45.
14. Acharya P, Pandey B, Pokhrel Y, Baral K, Munday D, Gongal R. Palliative care need among inpatients in acute general hospitals in Nepal: a point prevalence survey. 2017;4:42-46.
15. BK Manju, Munday D, Powys R. Noncommunicable Diseases and Palliative Care Needs: A Survey of a Rural Hospital in Nepal. In: *Indian Journal of Palliative Care*; 2017:121-179. <http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2017;volume=23;issue=2;spage=121;epage=179;aulast=>
16. Acharya P, Baral K, Munday D, N Gongal R. Population based need assessment of palliative care in rural Nepal. 2017;4.

17. Szekendi MK, Vaughn J, Lal A, Ouchi K, Williams MV. The Prevalence of Inpatients at 33 U.S. Hospitals Appropriate for and Receiving Referral to Palliative Care. *J Palliat Med.* 2016;19(4):360-372. doi:10.1089/jpm.2015.0236
18. Prasad R, Singh A, Garg R, Giridhar GB. Biomass fuel exposure and respiratory diseases in India. *Biosci Trends.* 2012;6(5):219-228.
19. Women's Commission for Refugee Women and Children. *The Perils of Direct Provision: UNHCR's Response to the Fuel Needs of Bhutanese Refugees in Nepal.* New York: Women's Commission for Refugee Women and Children; 2006.
20. Pokhrel AK, Bates MN, Verma SC, Joshi HS, Sreeramareddy CT, Smith KR. Tuberculosis and Indoor Biomass and Kerosene Use in Nepal: A Case-Control Study. *Environ Health Perspect.* 2010;118(4):558-564. doi:10.1289/ehp.0901032
21. Gordon SB, Bruce NG, Grigg J, et al. Respiratory risks from household air pollution in low and middle income countries. *Lancet Respir Med.* 2014;2(10):823-860. doi:10.1016/S2213-2600(14)70168-7
22. Barclay JS, Blackhall LJ, Tulsy JA. Communication Strategies and Cultural Issues in the Delivery of Bad News. *J Palliat Med.* 2007;10(4):958-977. doi:10.1089/jpm.2007.9929
23. Butow PN, Goldstein D, Bell ML, et al. Interpretation in Consultations With Immigrant Patients With Cancer: How Accurate Is It? *J Clin Oncol.* June 2011. doi:10.1200/JCO.2010.34.3335
24. Gongal RN, Upadhyay SK, Baral KP, Watson M, Kernohan GW. Providing Palliative Care in Rural Nepal: Perceptions of Mid-Level Health Workers. *Indian J Palliat Care.* 2018;24(2):150-155. doi:10.4103/IJPC.IJPC\_196\_17
25. Lamont EB, Christakis NA. Prognostic disclosure to patients with cancer near the end of life. *Ann Intern Med.* 2001;134(12):1096-1105. doi:10.7326/0003-4819-134-12-200106190-00009
26. Gongal R, Vaidya P, Jha R, Rajbhandary O, Watson M. Informing patients about cancer in Nepal: what do people prefer? *Palliat Med.* 2006;20(4):471-476. doi:10.1191/0269216306pm11540a
27. Puchalski C, Ferrell B, Virani R, et al. Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. *J Palliat Med.* 2009;12(10):885-904. doi:10.1089/jpm.2009.0142
28. Munday D, Powys R. Reflections on the challenges and opportunities for palliative care in Nepal. *Christ J Glob Health.* 2017;4(3):12-20. doi:10.15566/cjgh.v4i3.194
29. Puchalski CM, O'Donnell E. Religious and spiritual beliefs in end of life care: how major religions view death and dying. *Tech Reg Anesth Pain Manag.* 2005;9(3):114-121. doi:10.1053/j.trap.2005.06.003
30. Chakraborty R, El-Jawahri AR, Litzow MR, Syrjala KL, Parnes AD, Hahimi SK. A systematic review of religious beliefs about major end-of-life issues in the five major world religions. *Palliat Support Care.* 2017;15(5):609-622. doi:10.1017/S1478951516001061
31. Subba TB. *Politics of Culture: A Study of Three Kirata Communities in the Eastern Himalayas.* Orient Blackswan; 1999.
32. Weingaertner V, Scheve C, Gerdes V, et al. Breathlessness, Functional Status, Distress, and Palliative Care Needs Over Time in Patients With Advanced Chronic Obstructive Pulmonary Disease or Lung Cancer: A Cohort Study. *J Pain Symptom Manage.* 2014;48(4):569-581.e1. doi:10.1016/j.jpainsymman.2013.11.011
33. Choudhuri AH. Palliative care for patients with chronic obstructive pulmonary disease: current perspectives. *Indian J Palliat Care.* 2012;18(1):6-11. doi:10.4103/0973-1075.97342
34. Rocker GM, Simpson AC, Horton R. Palliative Care in Advanced Lung Disease: The Challenge of Integrating Palliation Into Everyday Care. *CHEST.* 2015;148(3):801-809. doi:10.1378/chest.14-2593
35. Nies MA, Febles C, Fanning K, Tavernier SS. A Conceptual Model for Home Based Primary Care of Older Refugees. *J Immigr Minor Health.* 2018;20(2):485-491. doi:10.1007/s10903-017-0610-8
36. Rocker GM, Verma JY. 'INSPIRED' COPD Outreach Program™: Doing the Right Things Right. *Clin Invest Med.* October 2014:E311-E319. doi:10.25011/cim.v37i5.22011
37. Kako J, Morita T, Yamaguchi T, et al. Fan Therapy Is Effective in Relieving Dyspnea in Patients With Terminally Ill Cancer: A Parallel-Arm, Randomized Controlled Trial. *J Pain Symptom Manage.* 2018;56(4):493-500. doi:10.1016/j.jpainsymman.2018.07.001
38. Bausewein C, Booth S, Gysels M, Kühnbach R, Higginson IJ. Effectiveness of a hand-held fan for breathlessness: a randomised phase II trial. *BMC Palliat Care.* 2010;9:22. doi:10.1186/1472-684X-9-22
39. Marchetti N, Lammi MR, Travaline JM, Ciccolella D, Civic B, Criner GJ. Air Current Applied to the Face Improves Exercise Performance in Patients with COPD. *Lung.* 2015;193(5):725-731. doi:10.1007/s00408-015-9780-0
40. Mularski RA, Reinke LF, Carrieri-Kohlman V, et al. An Official American Thoracic Society Workshop Report: Assessment and Palliative Management of Dyspnea Crisis. *Ann Am Thorac Soc.* 2013;10(5):S98-S106. doi:10.1513/AnnalsATS.201306-169ST
41. Murray B. Informed Consent: What Must a Physician Disclose to a Patient? *AMA J Ethics.* 2012;14(7):563-566. doi:10.1001/virtualmentor.2012.14.7.hlwa1-1207.
42. Fetters MD, Masuda Y. Japanese Patients' Preferences for Receiving Cancer Test Results While in the United States: Introducing an Advance Directive for Cancer Disclosure. *J Palliat Med.* 2000;3(3):361-374. doi:10.1089/jpm.2000.3.361
43. § 54.1-2986. *Procedure in Absence of an Advance Directive; Procedure for Advance Directive without Agent; No Presumption; Persons Who May Authorize Health Care for Patients Incapable of Informed Decisions.* <https://law.lis.virginia.gov/vacode/54.1-2986/>. Accessed June 22, 2019.

## Appendix A: Reproduced advance directive for disclosure

During your health check today, we will order one or more cancer diagnostic or screening test(s). The purpose of a screening test is to identify disease early when it is curable. Most cancer screening tests are negative. Still, screening tests can find both early stage, middle stage, and advanced stage cancers. Diagnostic tests are done to look for disease when the patient has symptoms.

As you may know doctors in Japan often do not tell patients when cancer is found. But in the United States, doctors almost always tell patients the truth. Given this cultural difference, we would like to learn of your preference in advance of finding the results so we can follow your preference.

You are receiving tests for \_\_\_\_\_

1. Most cancer screening tests are negative for cancer. If your test result shows there is no cancer, how would you prefer to receive today's results?
2. How would you prefer to be told if it was an early cancer with an 80%-90% chance of cure?
3. How would you prefer to be told if it was a middle stage cancer with a 30% to 70% chance of cure?
4. How would you prefer to be told if it was an advanced stage cancer with 20% or less chance of a cure?
5. How would the cancer type influence your preference for receiving the results?
6. If you have a positive cancer result, how would you prefer for your family members to be involved?
7. Was your health screening examination today required by your company?
  - a. Do you wish for your results to be sent to your company?
  - b. Can you explain why you feel that way?
  - c. Would the screening result, that is, a test negative for cancer or positive for cancer influence your preference for involving your company?
8. Has anyone in your family had cancer before?
  - a. Who was involved?
  - b. What happened?
  - c. How has that influenced your thinking about truth telling of the cancer diagnosis?

Is there anything else you think is important for me to know about cancer screening tests or disclosure of the cancer diagnosis?

## **Appendix B: Modified advance directive for disclosure**

At future health checks, we may order one or more cancer diagnostic or screening test(s). The purpose of a screening test is to identify disease early when it is curable. Most cancer screening tests are negative. Still, screening tests can find both early stage, middle stage, and advanced stage cancers. We may also order diagnostic tests for other serious conditions such as heart failure and COPD. Diagnostic tests are done to look for disease when the patient has symptoms.

As you may know doctors in some cultures often do not tell patients when cancer or other life-limiting disease is found. But in the United States, doctors almost always tell patients the truth. Given this cultural difference, we would like to learn of your preference in advance of any testing we may do so we can follow your preference. Unless we have told you differently today, we are not asking you these questions because we think you have cancer or another life-limiting disease.

You can change your mind about any of the answers you give today at any time and inform us of your change in preference.

1. Most cancer screening tests are negative for cancer. If a test result shows there is no cancer, how would you prefer to receive the results?
2. How would you prefer to be told if it was an early cancer with a high chance of cure?
3. How would you prefer to be told if it was a middle stage cancer with a medium chance of cure?
4. How would you prefer to be told if it was an advanced stage cancer with a low chance of a cure?
5. How would you prefer to be told if you are diagnosed with a chronic life-limiting illness and you would likely live 10+ years?
6. How would you prefer to be told if you are diagnosed with a chronic life-limiting illness and you would likely live for less than 2 years?
7. How would you prefer to be told if you are diagnosed with a chronic life-limiting illness and we are unsure how long you may live?
8. If you have cancer or another life-limiting illness, how would you prefer for your family members to be involved?
9. Has anyone in your family had cancer or another life-limiting illness before?
  - a. Who was involved?
  - b. What happened?
  - c. How has that influenced your thinking about telling a patient the truth about their diagnosis?

Is there anything else you think is important for me to know about your preferences and/or culture regarding cancer, illness or death?