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# Improving Cultural Approaches to Pediatric Palliative Care in Central Massachusetts


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# Improving Cultural Approaches to Pediatric Palliative Care in Central Massachusetts

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## **Comments**

Presented at the Medical Library Association Annual Meeting in Boston on Sunday, May 5, 2013.

# Cultural Approaches to Pediatric Palliative Care in Central Massachusetts

## Mission

Determine the impact of a web tool to improve health care providers' ability and comfort level in caring for a diverse patient population in the hospital setting.

## Objective

Provide cultural and palliative care information— resources, books and journal articles to assist health care workers at UMass Memorial Children's Medical Center in caring for children from the diverse cultural backgrounds living in the region.

## Evaluation

There is a plan to evaluate usage. The team will survey users at baseline and after they visit the Library Guide. We will survey Children Medical Center staff, including:

- Nurses
- Residents
- Attending Physicians
- Child Life Staff

## Palliative Care Subject Guide

Resource using SpringShare® software to create a Library Subject Guide. The subject guide is a collaborative project including Pediatric Oncology, the Lamar Soutter Library, Interpreter Services, and student interns.

## World's People in Central Massachusetts

## Mission and Guiding References

## Index of Cultures

## Religious Beliefs

## Culturally Sensitive Palliative Care

## Palliative Care Resources

## Pediatric Palliative Care Team

## Interpreter Services

## Interactive Index of Cultures



### Country specific information includes:

- Geography
- General Cultural Information
- Family Structure
- Communication Style
- Religious Practice
- Dietary Practices
- Concepts of Health and Wellness
- Local Community Information
- References

### Communication Style

Brazilians provide many details when offering information. They are always very courteous and will stop the conversation to summarize it for those who cannot keep up. They are comfortable with verbal confrontation, although confrontation does not happen between a younger and an older person. It is considered impolite to say 'no' directly to a health care provider; clinicians should not assume patients have necessarily concurred. Brazilians greet everyone with a hug. If the newcomer is a family member, friend, or acquaintance, a kiss on each cheek is included. Handshakes are appropriate when strangers are introduced or in formal situations, both for greetings and good-byes. If two men are well acquainted, a slap on the shoulder or stomach, or a sustained pat on the back, may accompany the handshake and last into the conversation. .

### BRAZIL



## World's People in Central Massachusetts

Demographic information was used to select the twenty-eight cultures and fifteen religions represented in the Library Guide

[http://libraryguides.umassmed.edu/diversity\\_guide](http://libraryguides.umassmed.edu/diversity_guide)

## Religious Beliefs

A word of caution must regularly be expressed when one is trying to speak absolutes about any religion. Within each denomination or belief system there are always variations. Geographic locations, generation gaps, gender differences, or cultural diversity may impact these convictions

Hinduism	
*3 <sup>rd</sup> largest religion in the world * Large populations in India, Nepal, and Bangladesh	
Birth	<ul style="list-style-type: none"> <li>• A wide variety of beliefs held together by an attitude of mutual tolerance and belief that all approaches to God are valid.</li> <li>• Hinduism's goal is to break free of this imperfect world and reunite with God</li> <li>• Reincarnation and karma (law of cause and effect)</li> <li>• One must perform his/her duties to God, parents, teachers and society</li> </ul>
Daily practices	<ul style="list-style-type: none"> <li>• Personal hygiene very important and bathing is required every day, but bathing after meal may be viewed as harmful</li> <li>• Hot water may be added to cold, but not the opposite</li> <li>• Removal of shoes before entering a room</li> </ul>
Dying and death	<ul style="list-style-type: none"> <li>• The atmosphere around the dying person must be peaceful</li> <li>• The last thoughts or words (see of God, the Gita scripture) is recited to strengthen the person's mind and provide comfort. Religious chanting before and after death is continually offered by family, friends, and priest.</li> <li>• Prefer to die at home, as close to mother earth as possible (usually on the ground)</li> <li>• Active euthanasia viewed as destructive</li> <li>• No Customs or restriction on prolongation of life</li> <li>• Immediately after death priest may pour water into mouth of deceased and family may wash the body</li> <li>• Customary for body not to be left alone until cremated</li> <li>• Autopsy and organ donation acceptable</li> <li>• Cremation is common on day of death</li> <li>• Fetus or children under age 2 may be buried, no rituals observed</li> </ul>
Facilitating practices	<ul style="list-style-type: none"> <li>• Provide supportive environment and privacy for rites</li> <li>• Involve family members in plan of care and determine which member will provide personal care</li> <li>• Father/husband is primary spokesperson to whom questions should be directed – women may not request special care</li> <li>• Special respect for elders</li> </ul>
Food	<ul style="list-style-type: none"> <li>• Usually vegetarian</li> <li>• If not vegetarian, may avoid beef or pork. According to dietary law, right hand is used for eating and left hand for holding and hygiene</li> <li>• May fast on special holy days</li> </ul>
Health	<ul style="list-style-type: none"> <li>• Prayer for health considered low form of prayer, stoicism is preferable</li> <li>• Medications, blood and blood products, donations and receipt of organs. See the following article: Thomas, Susan. <i>Hindu End of Life: Death, Dying, Suffering, and Karma.</i> <i>Journal of Hospice and Palliative Nursing</i>. 2010;22(8):337-342.</li> </ul>
Holy days and festivals	<ul style="list-style-type: none"> <li>• Several which are observed at home, some take place in a temple</li> <li>• Must be barefoot during religious worship or any kind of religious celebration</li> </ul>

## Usage

In the first quarter of the 2013, usage of the guide has been over 3,000 hits. It has received more hits than any of the other guides produced by the Lamar Soutter Library. In addition to health professionals, we understand the public is also visiting the guide.