

Editorial

## Religious, and Ethno-Cultural Competence in Palliative and End-of-Life Care

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### Abstract

Cultural and religious competence is an essential component of palliative and end-of-life care. Because religious, ethnic and racial groups often differ in their values and preferences, including their attitudes toward palliative and end-of-life care, clinicians must maintain an open and respectful attitude toward these differences. Cultural and religious competence can improve



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palliative and end-of-life care, and strengthen the therapeutic alliance with patients and their families.

### **Keywords**

Palliative; end-of-life; cultural; ethnic; religious; racial

## **1. Introduction**

As Swihart and Martin note,

*“...cultural competence is the ability of health providers and organizations to deliver health care services that meet the cultural, social, and religious needs of patients and their families. Culturally competent care can improve patient quality and care outcomes...[conversely]*

*if providers and health care systems are not working together to provide culturally competent care, patients may have untoward health consequences, receive poor quality care, and be dissatisfied with the care they receive.” [1]*

In this editorial essay, we summarize aspects of cultural and religious competence in relation to *palliative* and *end-of-life* care, which are related but distinct terms. Essentially, *palliative care* is a team-based approach to care for people with serious illness that is appropriate at any age/stage of illness. Palliative care is focused on improving the quality of life for individuals facing serious and life-limiting illness, and on providing symptom management and pain relief. *End-of-life* care provides palliative care for terminally ill individuals who may have only very limited time to live and have elected to no longer pursue curative treatment. It is often tied to hospice care, which is defined in the United States as encompassing the final six months of life. [2]

We begin by examining cultural and religious competence in the context of the three Abrahamic religions, followed by brief discussion of Buddhism and Hinduism. We then summarize salient racial and ethno-cultural issues in palliative and end-of-life care. We caution that our brief discussion cannot capture the depth and complexity of the religious and spiritual traditions we consider; and that our summary is limited mainly to those aspects of these faiths most relevant to palliative and end-of-life care.

## **2. The Abrahamic Faiths**

Judaism, Christianity and Islam are often called “the Abrahamic faiths,” because the Biblical figure of Abraham is important in all three religions, and because they share fundamental monotheistic beliefs. Accordingly, we consider these three religious traditions together.

## 2.1 Judaism

At any stage of illness—including at end-of-life —persons of the Jewish faith may express specific, faith-based needs and preferences, with respect to palliative care. However, these may differ considerably, depending on whether the patient identifies with Orthodox, Conservative, Reform, or Reconstructionist Judaism. “Orthodox” Judaism is itself a heterogeneous designation, and includes several sub-denominations of differing religious, cultural, and political values. [3] In general, however, Orthodox Judaism tends to have more restrictive or specific concerns with respect to how palliative care, including care at end-of-life, is provided. For example, many Orthodox Jews are *shomer negiah*, which literally means, “observant of touch.” [4] This means that one refrains from physical contact with members of the opposite sex (though immediate family members are usually exceptions). Thus, a well-meaning pat on the shoulder from a female physician may be experienced as a boundary violation by a *shomer negiah* Orthodox Jewish man.

The principle of the patient’s *autonomy* is one of the four cornerstones of medical ethics, along with *beneficence*, *non-maleficence*, and *justice*. [5] However, as a rough generalization, the patient’s “autonomy” in medical decision-making is not emphasized in Orthodox Judaism. Rather, Orthodox tradition places great reliance on the physician’s directives, with which the patient is—with some exceptions—generally expected to comply. In contrast, within the Conservative and Reform movements, the right of individuals to make decisions concerning their health care, including the right to refuse such care, is typically given greater weight.

The position of Orthodox Judaism with respect to end-of-life care may be summarized as follows:

*“Jewish tradition generally requires that every effort be made to sustain and extend life, but that position is not absolute. In cases where diseases cannot be cured and medical interventions would be risky, painful, of uncertain efficacy or serve merely to prolong a life of unbearable physical or psychic pain, there is support in Jewish law for an individual’s right to reject such treatment.”* [6]

That said, there is near unanimity in rabbinic Judaism that euthanasia (“mercy killing”) and *physician assisted suicide* --sometimes inappropriately called, “medical aid in dying”-- are strictly prohibited. However, there is broad support among most rabbinic authorities for “removal of impediments” to death, when there is no hope for the patient’s recovery and the patient is in considerable physical or emotional pain. So, for example, discontinuation of “heroic measures”, such as needlessly keeping the dying patient on a respirator, would generally be allowed in such cases, under the “removal of impediments” principle. While there are variations among Jewish denominations—and certainly among rabbis--the following statement by Rabbi Elliot N. Dorff may be considered generally representative of Jewish thinking:

*“Even though Jewish law...goes quite far in permitting terminally ill patients to die with whatever palliative care they need and without any further medical interference, it does not permit suicide or assisted suicide. The tradition bids us instead to maintain a firm line separating permissible withholding and withdrawal of medical efforts, on the one hand; and illegitimately helping a person actively to take his or her own life, on the other. To fail to do that would be to violate Jewish law and to destroy creatures belonging to God.”* [7]

As Rabbi Mark A. Popovsky has noted, the strong Jewish commitment to maintaining life may lead some terminally ill Jewish patients to reject palliative or hospice care. However, "...the values underlying palliative care and hospice are in fact consistent with Jewish values at the end of life," and "...proper palliative care in a Jewish context is careful to avoid any intervention which might actively hasten death." [8]

The foregoing discussion highlights only a few of the many issues involved in the care of critically or terminally ill Jewish patients. For further explication, the reader is referred to the comprehensive monograph by Rabbi Popovsky.

## **2.2 Christianity**

Christianity has an ancient history of providing integrative palliative care during the ancient and medieval periods that promoted holistic healing of body, mind and soul. Christianity teaches that through faith in the death and resurrection of the God-man Jesus Christ God, the individual soul is delivered from sin, sickness, and suffering and receives eternal life. "Everyone who calls on the name of the Lord will be saved." (Matt 7:21 RSV) As the great historian of the subject, Darrel Amundsen, has noted, "Indeed the, the very essence of Christianity had that as its goal." [9] Until the High Middle Ages, many monastic priests were also physicians providing both pastoral and medical care, especially for those who were sick and dying.

There was, in this time, only one Church. Beginning in 1054 with the split between what has become the Roman Catholic Church in the West and the Eastern Orthodox Church in the East, the Church that Christ prayed would be united has continued to divide. The Reformation in the sixteenth-century resulted in the other major division--that between Roman Catholicism and the many Protestant faiths.

Although any broad claims risk exceptions, in general, more fundamentalist and/or evangelical faith traditions that uphold a more literal interpretation of Scripture--and more conservative views on social and reproductive issues--tend to embrace a belief in miraculous cures and to favor more aggressive end-of-life care. Ethically, they often share with mainstream Roman Catholics a set of religious beliefs that influence decisions about end-of-life care. The sanctity of life--even physiologic life without higher cognitive or relational abilities--is among the most important values that can lead to conflicts when medical teams recommend a more palliative approach. While the faith commitments of most of these groups may permit the withdrawal or withholding of life-sustaining treatment in terminal illness, or when a patient is dying, they usually do not approve of assisted suicide or euthanasia, believing that a sovereign God is in control of life and death. In a 2018 survey of over 1,000 American (mostly Christian) clergy, Babloni and colleagues suggest this constellation of beliefs may discourage advance care planning and discussions about limiting life-sustaining treatment, which are key aspects of palliative care.[10]

This discrepancy became a controversy in the media when it was widely misreported that Pope John Paul II had said that Catholics could not forego artificial nutrition and hydration--contrary to a long theological and pastoral tradition holding that the preservation of life does not require extraordinary means. Catholic bioethicist and internist Daniel Sulmasy provided a much need

clarification for believers. In a widely-read Catholic magazine (3), Sulmasy summarized Church teachings as follows:

- We should never euthanize patients or assist them in suicide;
- Sometimes certain life-sustaining treatments (including feeding tubes) are “extraordinary” (morally optional) and may be withheld or withdrawn;
- Special care must be taken in determining that feeding tubes are “extraordinary,” particularly if the patient suffers from a rare neurological condition called post-coma unresponsiveness. [11]

More liberal Protestants such as Episcopalians--and some Lutherans, Presbyterians and others--embrace attitudes closer to secular views and locate the locus of decision-making in the conscience of the believer, rather than in the teachings of the Church or the authority of Scripture.

These denominations tend to have a more positive view of medicine and science and are more open to advance care planning and palliative care, although most do not approve of physician-assisted suicide or euthanasia.

Despite their belief in redemptive suffering, Catholics--as well as many Protestants--affirm the moral theological principle of double-effect. This holds that pain medication can be provided to relieve suffering, even if it hastens death, so long as death is not the *intention* of the physician, or the direct means by which the physician relieves the suffering. Shorn of any religious associations, this is also the ethical justification for the work of palliative care physicians, whose training and focus are on providing comfort care that enhances the quality of life rather than prolonging its quantity or extending dying. This ethical reasoning can also support the use of palliative sedation when even the best efforts of expert palliative care teams cannot adequately control pain or other psychophysical distress.[12]

### **2.3 Islam**

Islam is a diverse faith, and beliefs and practices often differ between *Sunni* and *Shia* branches of the faith. (The vast majority of Muslims—about 85%--are Sunni). Attum et al have succinctly summarized the cultural and religious issues involved in caring for Muslim patients. They note that

*“The Muslim faith encompasses several ethnicities with diverse views regarding illness and healthcare. As a result, the care of Muslim patients provides challenges for many non-Muslim healthcare providers. The Islamic faith can influence decision-making, family dynamics, health practices, and risks and the use of healthcare.”* [13]

These authors add that “Muslim patients believe illness, suffering, pain, and dying [come] as a test from God, and perceive illness as a trial by which one’s sins are removed.” This perspective may differ markedly from that of most secularly-oriented caregivers, and may thus be a source of patient-staff friction.

Attum et al note some specific concerns that apply to Islamic hospice patients and palliative care:

*“Many Muslim and Arab patients do not expect health professionals to tell them or remind them of their terminal illness. Hospice care may help the Islamic family fulfill a cultural and religious obligation if the focus is on comforting the patient, rather than helping them to accept impending death. It is not uncommon for Muslim patients to not*

*give up hope because they believe God has the power to create life and as well as cause death.” [13]*

On the other hand, in Islam, death is often seen as part of “God’s plan.” And, as in Judaism, euthanasia is strictly prohibited in Islam. Confession of sins and begging forgiveness may occur in before death.

### **3. Non-Abrahamic Faiths and Traditions**

#### **3.1 Buddhism and Palliative Care**

Although Buddhism and Christianity are, on one level, very disparate traditions, the belief that suffering is to be endured and transcended links them. To be sure, Buddhism, unlike Christianity, is atheistic; denies the existence of the individual soul; and affirms the karmic cycle of death and rebirth. And, as the Buddha said to his monks upon his own death, “Therefore Ananda, be ye lamps unto yourselves.” [14] Yet no less than the revered Buddhist scholar Thich Nhat Hanh has illuminated the affinity of Buddhism and Christianity in their founder’s missions to relieve and transcend suffering through mercy and compassion. “I believe that if anyone, Buddhist or Christian, embraces suffering with his or her own mindfulness or allows the Holy Spirit to work within himself, he will come to really understand the nature of that suffering and will no longer impose on himself or others dogmas that constitute obstacles for working toward the cessation of that suffering.” [15]

There are two main branches of Buddhism, *Theravada* (or *Hinayana*) and *Mahayana*, of which the Zen Buddhism so popular in the West is an offshoot. The origins of Buddhism 2,600 years ago lie in Buddha’s compassion for aging, sickness, suffering and death that gave rise to the modern hospice movement. The Buddha--through spiritual exercises that led to the cessation of egotistic desire--reached a state beyond suffering, yet was suffused with compassion for all beings.

When Buddhists approach the end-of-life, they seek clarity of mind and equanimity of spirit because these qualities transitively influence the next rebirth. Buddhists share palliative care’s critique that much of our modern technological medicine makes a peaceful death nearly impossible to achieve. Masel and colleagues emphasize how much Buddhists have to teach palliative care practitioners, and all who seek to facilitate a calm and harmonious dying process.

Medical staff may build intense relationships with patients being admitted to palliative care units. Buddhism may be used by staff as an inspiration for patients, although it should not be suggested as a method. The feeling of not being able to offer something to a patient can lead to distant behavior on the part of the staff. In this regard, Buddhism can be helpful to medical staff by emphasizing the importance of using all possible wisdom and compassion to relieve human suffering.

In advanced illnesses that cannot be cured, compassionate care as a central element of Buddhism can help medical staff in trying to relieve patient suffering. [16] At times, this can lead to tension with treatment teams who feel they have a professional duty to aggressively manage pain at the end-of-life; or with family members who insist that all traces of suffering be erased. Conversely, several recent articles describe how empathic respect for Buddhist values of acceptance and support can

enable a patient to die with tranquility, even in the “high-tech” environment of the intensive care unit. [17]

Those with a superficial knowledge of the Buddhist tradition frequently presume it endorses physician-assisted suicide (PAS) and euthanasia as definite means to end suffering. A deeper acquaintance with Buddha’s teaching reveals that PAS and euthanasia are in fact an attempt to spiritually short-cut the moral law of the universe, Karma, for which every word, thought and action has moral consequences determinative of the person’s character and rebirth. Taking one’s own life or that of another violates *Ahimsa*--the primary Eastern ethical doctrine that combines the Western principles of *beneficence* in respecting all living beings; and that of *non-maleficence* in avoiding all harm or violence toward them. [18]

#### **4. Hinduism**

Hinduism—the third largest religion in the world-- is also one of the world's oldest faiths, dating back more than 4000 years. Although often portrayed as prolifically polytheistic, Hinduism is arguably *monist* in its ontology, in that it recognizes *Brahman* as the “ultimate reality” in the universe. Hinduism does not espouse an authoritative “creed,” akin to the Nicene Creed of Christianity, and generalizations regarding Hindu beliefs must be considered first approximations, at best. Nevertheless, Swihart and Martin summarize some key Hindu beliefs relating to palliative and end-of-life care. [1]

First—as with Buddhism--the concept of *karma* is fundamental to Hinduism. Karma implies that pain and suffering are seen as a result of one’s prior actions; and that one’s future lives are influenced by how one faces illness or death. Accordingly, in Hinduism, the atmosphere around the dying person must be peaceful; and, ideally, dying should occur at home. This expectation is obviously in tension with the need for palliative or end-of-life care in institutional settings, and may occasion regret or guilt on the part of some Hindu patients or their families.

In Hindu tradition, euthanasia is forbidden. For adults, cremation is common on the day of death, and the body of the deceased is not to be left alone until cremated. In traditional Hinduism, immediately after death, the family may wash the body and the priest may pour water into the mouth of the deceased. Recitation of sacred texts, such as the *Bhagavad Gita*, may provide comfort to the bereaved family. Clearly, such rituals and customs are difficult to honor in most palliative or end-of-life settings in the U.S. However, the clinician should be aware that some Hindu patients or their families may request some accommodation of these practices. [1]

#### **5. Racial and Ethno-Cultural Issues in Palliative and End-of-life Care**

There are no simple, universally applicable guidelines for the care of critically or terminally ill patients representing racial and ethnic minorities—except perhaps that each such group requires an individualized approach. This is particularly important since

*“If [clinicians]...do not understand cultural differences in care preferences or do not ask questions about one's cultural identity (including sexual orientation and gender diversity)*

*in a culturally sensitive way, it may result in negative outcomes for individuals and families, including their preferences not being honored.” [19]*

A complete survey of racial and ethno-cultural minorities and their health care needs is beyond the scope of this editorial. For a detailed discussion, the reader is referred to the excellent synopsis by Givler and Maani-Fogelman. [20]

Accordingly, we will focus on the three largest racial and ethnic groups in the U.S.; namely, African-Americans; those of Hispanic or Latino origin (also called “Latinx” to avoid gender bias); and those identified as Asian. According to the U.S. Census Bureau, Hispanic and Asian populations were the fastest growing minority groups in the U.S., during the period from 2000 to 2010. [21]

We must caution, however, that broad-brush terms such as “Black,” “Hispanic” or “Asian” are scientifically inexact and somewhat misleading. Indeed, some would argue that these are largely “socially-constructed” terms of convenience that often conceal more than they reveal. Thus, considerable heterogeneity of cultural and spiritual values may be found among Asian, African-American, Latinx/Hispanic, and other “non-white” racial and ethnic groups.[22]

With these caveats in mind, we can offer a few general remarks with respect to the three largest U.S. minority groups, and their attitudes toward palliative and end-of-life care.

- **African-American patients:** Rhodes and colleagues have outlined a number of “barriers” to optimal palliative and end-of-life care, among African-American (AA) patients. Thus, hospice and palliative medicine clinicians have noted that AA patients’ spiritual beliefs often conflict with the hospice and palliative medicine philosophy of care. For example, AA patients “...often expressed a desire to “leave it in God’s hands” or believed that “God will take care of” them...” making discussion of end-of-life care “more challenging.” In addition, health care workers cited a desire for more aggressive care among AA patients as a barrier to advance care planning, use of palliative care, and use of hospice. [23] In part, AA patients may insist on this more aggressive care and be somewhat resistant to advance care planning due to a lack of trust in the healthcare system. This mistrust reflects the tragic historical failure of American medicine and research to respect African-American values and interests. [24]

- **Hispanic/Latinx patients:** Latinos are the largest ethnic minority group in the US, currently accounting for 15% of the US population, and this group is projected to grow to 30% by the year 2050. Unfortunately, as Smith et al have observed, “For non-Latino and non-Spanish-speaking clinicians, communication barriers and cultural misunderstandings can impede the care of dying Latino patients and their families.” [25]

Furthermore, cultural attitudes common in Latinx populations may affect how palliative and hospice care in the U.S. is perceived. For example, in a US survey, not informing the patient of a poor-outcome fatal disease was preferred by about a third of older Mexican Americans, as compared with less than 15% of whites or African Americans. At the same time, some evidence suggests that Latinos “...expect physicians to take a more directive role with regard to decisions regarding life-sustaining treatment.” [25] Bedolla has pointed out that for many older Mexican-Americans, the ethical principle of beneficence take primacy over autonomy, a prioritization that reverses the assumptions of most health care professionals. [26]

In addition, Smith et al point out that, while patterns differ individually and within the Latinx community, three cultural “scripts” (patterns of social interaction) are common in Latinx culture: *familismo*, *machismo*, and *fatalismo*. Roughly translated, these refer, respectively, to *the importance of family in decision-making; the need for Latino men to serve as “protector” of the family; and the belief that one's future is pre-ordained.*

As Marques et al explain,

*“Familismo [refers to]...preference to age at home and not use formal care services. Both men and women mentioned the value of familismo and the notion that if their loved ones are put in homes then they will not receive love and proper care, and therefore, die faster... Machismo was noted in descriptions of actions as men’s duties to protect their family. Fatalismo was cited as ways to express gratitude for positive situations, and appreciation for avoidance of negative situations.” [27]*

- **Asian Patients:** The term “Asian” must be applied with care, since it covers an enormous geographical, cultural and religious territory; furthermore, there is considerable variation in mores, customs and values when considering groups as diverse as Asian Indians and Vietnamese or Chinese.

Indeed, as Kim et al have observed,

*“Failure to recognize the uniqueness of specific Asian American ethnic groups...may be contributing to a “homogenized” view of Asian Americans, despite the fact that there are over 25 ethnic subgroups of Asian ancestry who reside in the United States.” [28]*

This homogenization may obscure important differences in personal and cultural values. For example, Kim et al [28] found that Japanese Americans espoused more traditional Asian values than did Chinese, Filipino and Korean Americans. Nevertheless, since Chinese Americans represent the largest proportion of Asian Americans in the United States, we will focus primarily on this group.

In a study of end-of-life (EOL) care among Chinese Americans, Lee et al cited a number of challenges for clinicians. For example,

*“In traditional Chinese culture, discussion of death and dying is taboo and thought to bring bad luck to one’s family. Initiating a discussion about these topics is traditionally considered disrespectful. [Furthermore], in managing EOL care of parents, a good and “filial” child is expected to do everything to prolong their parents’ life.” [29]* This expectation has generated ethical conflicts between the ethical principles of truth-telling and informed consent that govern modern Western medical ethics and the duties of filial piety so important in Chinese society.[30] It is crucial for health care professionals to balance these considerations through ensuring that the individual patient wishes to defer discussions and decisions at the end-of-life to their adult children.

In addition,

*“In traditional Chinese culture, the concepts of living in a nursing home away from family, or needing to be “cleaned up” by others who are not family members are examples of losing dignity for the individual and not fulfilling Xiao [filial piety] by their children.” [29]*

Among the physical needs at EOL, being pain-free was the top element of a good death in the population studied by Lee et al. This study also found that “Prayer and spirituality were seen as essential to a good death in Chinese Americans”, and that “patients at EOL found peace and comfort

through prayer.” Another psychosocial need considered part of “a good death” included having family members present to create a sense of security and comfort.

While we have focused on Chinese populations, the emphasis on family involvement in EOL care seems true of Asian patients generally. For example, a study of EOL care in Asian Indian patients found that:

*“Traditional cultural values, such as duty to family, greatly influenced end-of-life care preferences and retained importance across generations.... When eliciting Asian Indian patient preferences for end-of-lifecare, clinicians should consider explicitly asking about preferences related to family involvement in care, decision control, and communication; and explore the role of traditional expectations and specific social realities for each patient.”* [31]

(Not only Asians, but also more traditional Latino and Native American cultures often eschew individualistic autonomy in medical decision-making, preferring a concept of family autonomy. Palliative care professionals may need to adopt the goal of holding care discussions with a group of extended family as the locus of decisions about palliative and hospice care.)

To summarize this brief, and necessarily incomplete, overview, the following generalizations may be helpful, while bearing in mind the wide range of intra-cultural and personal preferences:

*“African, Asian, Chinese, East Indian, Hispanic, Indonesian, Japanese, Native American, and Vietnamese families may request providers not to disclose a terminal diagnosis as they want to avoid emotional suffering and preserve hope... Chinese people may believe pain results from an imbalance between yin and yang. Some cultures believe they should endure pain bravely and serve as a role model, perhaps to improve their standing in life after death. Some cultures may believe pain may be a sign of progress toward recovery. Some cultures, such as American Indian, Asian, Black, [and] Hispanic, are very stoic regarding pain and may maintain a neutral facial expression despite being in severe pain. Some religions may believe pain is a part of God's plan, a test of faith, or penance for past sins.”* [20]

## **6. Conclusion**

In this essay, we have attempted to depict the wide range of religious, spiritual, cultural, and ethnic values, concerning palliative and end-of-life care. We recognize that our synopsis provides, at best, a compendium of rough generalizations, with the expectation that exceptions will be frequently encountered; thus, clinicians must be careful to avoid stereotyped assumptions. The clinician faced with unfamiliar religious, cultural or ethnic practices is best served by “digging down” into the values of the specific patient and his or her family. Consulting cultural and religious advisors such as chaplains or representatives from the patient’s community can help practitioners avoid cultural insensitivity and foster respectful understanding of religious beliefs unfamiliar to the practitioner. In many instances, the secularly-oriented clinician may have a markedly different perspective from that of the traditionally religious patient, or that of a particular ethnic or cultural group. In such cases, awareness of one’s biases; adherence to fundamental moral virtues, such as respect and compassion;

attentive listening; and cultural sensitivity are critical in approaching palliative care and end-of-life issues.

### **Author Contributions**

Dr. Geppert was primarily involved in writing the sections on Christianity and Buddhism and contributed to all sections; Dr. Pies was primarily involved in writing the sections on Judaism, Islam and Ethno-cultural/racial attitudes. Both Dr. Geppert and Dr. Pies reviewed and approved all aspects of the manuscript.

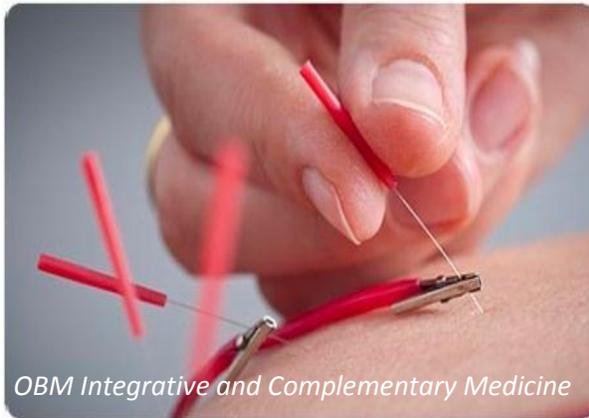
### **Competing Interests**

Dr. Geppert and Dr. Pies have declared that no competing interests exist with respect to this manuscript.

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