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ORIGINAL PAPER

Prevalence and Nature of Spiritual Distress Among Palliative Care Patients in India

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Abstract In palliative care research, little attention has been paid to the empirical study of spirituality in patients in non-Western countries. This study describes the prevalence and nature of spiritual distress among Indian palliative care patients. Data from 300 adult cancer patients who had completed a questionnaire with 36 spirituality items were analyzed. Spirituality was shaped by the Indian religious and economic context. A latent class analysis resulted in three clusters: trustful patients (46.4 %), spiritually distressed patients (17.4 %), and patients clinging to divine support (36.2 %). After regression, the clusters were found to be associated with pain scores ($p < .001$), gender ($p = .034$), and educational level ($p < .006$). More than half of the patients would benefit from spiritual counselling. More research and education on spirituality in Indian palliative care is urgently required.

Keywords Spirituality · Cancer · Palliative care · India

Introduction

In the first decades after the Second World War, Cicely Saunders developed the benchmarks of the modern hospice movement, which would later on evolve into palliative care. Through her work first as a nurse and later as a physician who cared for dying patients, she had become very much aware of the need to address spiritual issues and concerns in

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terminally ill patients, because "the medical and spiritual are inextricably mingled," as she wrote in one of her letters in 1960 (Clark 2001). Since then, the scientific evidence of the spiritual needs of palliative care patients has been growing (Cobb et al. 2012; El Nawawi et al. 2012). On the basis of that evidence, researchers have come to the conclusion that patients' spiritual well-being can be so poor that "spiritual distress" has been considered an appropriate diagnosis, although the concept "spiritual distress" has not been very well defined in the literature. In nursing literature, spiritual distress has been described as a "state of suffering related to the impaired ability to experience meaning in life through connectedness with self, others, world, or a Superior Being" (Caldeira et al. 2013).

Such understanding of spiritual distress is tied up with particular interpretations of spirituality. In the last decade, scholars have attempted to find a consensus definition of spirituality in palliative care. Notwithstanding the fact that fruitful attempts at such a definition have been made (EAPC 2015; Puchalski et al. 2009), a single final definition that would be adopted by the worldwide palliative care movement has remained elusive. The reason for this may even go beyond the fact that the object or state of mind to which the concept spirituality refers to is difficult to delineate. Spirituality's very meaning and importance may be unstable and vary between cultures. Even among Western countries, there may be differences in how spirituality is interpreted and experienced. Already in 2002, Walter argued that the spirituality discourse that we find in palliative care literature is particular to specific segments of the population in Anglophone countries and may not correspond to how most patients actually experience spirituality (Walter 2002).

If there is discussion about the meaning of spirituality in Anglophone countries, the differences between Western and Eastern countries, such as India and China, may be even more substantial. Unfortunately, at present, we do not have much data regarding spirituality among palliative care patients in these countries. Most of the empirical studies on spirituality in palliative care have been conducted in the USA and the UK (Cobb et al. 2012). In India, palliative care programs of all kinds, such as hospices, home care teams, volunteer services, and outpatient clinics, have been developing since the late 1980's (McDermott et al. 2008; Rajagopal and Palat 2002; Shanmugasundaram et al. 2006); however, very few studies among Indian palliative care patients have taken spirituality as their primary object (Banerjee et al. 2007; Kandasamy et al. 2011; Lewis et al. 2014; Selman and Higginson 2010; Simha et al. 2013; Wright et al. 2004).

The limited attention that has been paid to the study of spirituality in palliative care in India should make us wonder to what extent spiritual care in Indian palliative care is evidence based. This question becomes even more relevant when we consider that the limited data that are available seem to indicate that spirituality in Indian palliative care substantially differs from spirituality in Western palliative care contexts where most of the spirituality research has been conducted. Therefore, results from spirituality studies outside India cannot readily be extrapolated to the Indian palliative care population. An indication of the reality of the differences can be found in the study of Kudla et al. (2015), who observed that Indian palliative care patients more frequently associate meaning in life with spirituality than German palliative care patients. The reason that underlies this dissimilarity could be the very different nature of the sources of meaning to which palliative care patients in India take recourse.

In Indian palliative care, religion, for instance, could be a more prominent source of meaning. In the small-scale qualitative study of Simha et al. (2013), it was noted that concerns related to Indian religiosity, such as belief in karma and rebirth, were common among the studied hospice patients. Karma and rebirth are concepts that can help patients give a metaphysical explanation to their suffering, so they are, in that capacity, sources of

meaning. More generally, research seems to indicate the very important role of religion in spirituality in Indian palliative care. This is also what the study of Simha et al. (2013) shows. In that study, it was found that almost all patients found it impossible to distinguish between spirituality and religion. A recent systematic review on spirituality in Indian palliative care further showed that religion figured prominently in all studied dimensions of spirituality (Gielen et al. 2015). In that review article, this observation led to the conclusion that Western definitions of spirituality, where religion is only one aspect of spirituality alongside many others, may not be applicable to Indian palliative care where religion plays a much more prominent role.

If Western definitions of spirituality in palliative care cannot be applied to palliative care in India, then research tools that have been based on these definitions may not be useful either. This could be the reason why Chandra et al. (2006), who studied the association between quality of life and HIV infection in South Indian HIV-infected patients, did not find an association between the spiritual domain of quality of life and advancing HIV disease. HIV patients often have palliative care needs. The investigators found this absence of an association remarkable, because they had observed associations with other domains of quality of life. They attributed the absence of an association with the spiritual domain to deficient measurement of spirituality in the tool that they had used for the study: the WHOQoL BREF. A culturally adapted measurement of spirituality could have led to different findings.

These observations all point toward the particularity of spirituality in Indian palliative care. Given this particularity and the scarcity of available scientific findings, we decided to conduct a quantitative study on spirituality in Indian palliative care using a questionnaire that was specifically designed for this context. We were interested in the prevalence and nature of spiritual distress among Indian palliative care patients.

Method

For this study, we used data that had been collected while developing a new questionnaire for the study of spirituality in Indian palliative care. The development of this questionnaire and the data-collecting process have been elaborately described elsewhere (Bhatnagar et al. 2016). Steps that led to the questionnaire included a systematic review of the literature on spirituality in Indian palliative care (Gielen et al. 2015), an ethnographic study (Gielen 2014), consultation of experts, and a pilot study of the questionnaire. The final questionnaire was in Hindi and contained 36 spirituality items. The respondents were also asked to provide demographic information, including age, gender, marital status, diagnosis (open-ended question: "What do you know about your illness?"), prognosis (closed-ended question: "How would you rate your prognosis?" Answer categories: "I do not know anything about my prognosis," "Very poor," "Poor," "Neither poor, nor good," "Good," "Very good"), educational level, and religious affiliation. Experience of pain was measured with a numerical rating pain scale. From September to December 2014, two trained interviewers administered the questionnaire to 300 Hindi-speaking adult patients who were undergoing treatment at the pain clinic of a tertiary cancer hospital in New Delhi and had consented to participate in the study. The study had been approved by the Ethics Committee (Institutional Review Board) of the All India Institute of Medical Sciences (AIIMS, New Delhi) where the study was conducted.

We undertook descriptive analysis of the individual spirituality items. In order to gain a more systematic insight into the nature and prevalence of spiritual distress, we decided to perform a latent class analysis on the patients' responses to the 36 spirituality statements. This analysis would allow us to divide the patients into different clusters or groups, each of them containing patients with similar spiritual issues and concerns, which, in turn, would be indicative of the kind of spiritual distress experienced by them. To assess the effect of demographic variables and pain scores on the spirituality clusters, we used the Pearson Chi-square and Kruskal–Wallis tests. Alpha levels of >.05 were considered significant.

In cases of significant associations, we would use the multinomial logit model and perform a likelihood ratio test to check whether these associations remained significant while controlling for the other covariates that were found to be significantly associated with the spirituality clusters in the analyses outlined above.

For the statistical analysis, IBM SPSS Statistics 22 was used. For the latent class analysis, the poLCA-package (Linzer and Lewis 2011, 2013) in R 2.15 (www.r-project.org) was utilized. R was called from SPSS with IBM SPSS R Essentials.

Results

In the sample, the number of male ($n = 152$, 50.7 %) and female ($n = 148$, 49.3 %) patients was almost equal. Patients tended to be middle-aged adults, with the mean age at 47.5 (SD 12.4). Only a minority of the patients ($n = 29$, 9.6 %) were not married at the time of the interview, being either unmarried, widowed or divorced. Many patients (28 %, $n = 84$) were uneducated, 44.3 % ($n = 133$) had studied until tenth grade (16 years), 11.7 % ($n = 35$) had completed intermediate education (18 years), and 15.7 % ($n = 47$) had at least a graduate degree. A large majority (80.3 %, $n = 241$) was Hindu, with the remaining patients belonging to various religious minorities (Muslim, Sikh, Jain, Christian, and Buddhist). All participants were suffering from cancer-related pain, with CA breast ($n = 45$, 15 %) being the most common cancer followed by CA lung ($n = 26$, 8.7 %), CA gallbladder ($n = 15$, 5 %), and CA rectum ($n = 13$, 4.3 %). The mean pain score for all patients was 3.22 (SD 2.10) on a scale from one ("no pain") to ten ("worst possible pain"). 40.3 % ($n = 121$) rated their prognosis as either "good" or "very good," 28.4 % ($n = 85$) as "poor" or "very poor," and 14 % ($n = 42$) as "neither poor, nor good." 16 % ($n = 48$) attested that they did not know anything about their prognosis.

In Table 1, we give the patients' responses to the spirituality items.

The results showed that anger is a common occurrence among patients in Indian palliative care. More than half of the patients (55.3 %) felt angry because of what was happening to them. Most of the patients did not seem to be angry with God or another form of Ultimate Reality, because a majority believed that God was with them (88.3 %) and some higher power supported them (78.9 %). Most patients relished their relationship with the divine, and they attested to derive a feeling of peace from religious practices (83.3 %). They also asserted that such activities made them feel better (90.3 %). Indeed, only 7.7 % expressly denied that their faith in a higher power was a source of support.

Possibly, some of the patients were angry with themselves, as 64.7 % blamed themselves for the illness. This aligns with the observation that almost two-thirds saw their illness or pain as a punishment for wrong done by them (64.2 %), or more explicitly as a punishment from God (66 %). Even more patients agreed with the statement that their illness was a consequence of karma (74.9 %). In that manner, they indirectly expressed that

Table 1 Agreement with spirituality statements

		n	Agree	Neither agree nor disagree	Disagree
1	I am angry because of what is happening to me	300	55.3 % (166)	4.3 % (13)	40.3 % (121)
2	I am worried about what will happen to my children and/or spouse in case I do not get better	300	72.3 % (217)	4 % (12)	23.7 % (71)
3	God is with me	299	88.3 % (264)	4.7 % (14)	7 % (21)
4	Since the onset of my illness, I have become less interested in thinking about God or religion	300	32.7 % (98)	2.3 % (7)	65 % (195)
5	There is some higher power that supports me	299	78.9 % (236)	6 % (18)	15.1 % (45)
6	I wonder why this illness has happened to me	300	83.3 % (250)	2 % (6)	14.7 % (44)
7	I find it difficult to forgive others for wrong they did to me	300	29 % (87)	4.7 % (14)	66.3 % (199)
8	This illness is unfair	300	76.3 % (229)	7.7 % (23)	16 % (48)
9	I wonder what will happen after death	299	54.2 % (162)	11.7 % (35)	34.1 % (102)
10	I am afraid of the future	299	55.5 % (166)	1.3 % (4)	43.1 % (129)
11	I feel lonely	298	57.7 % (172)	2 % (6)	40.3 % (120)
12	*Pūjā* is a source of peace for me	299	83.3 % (249)	6 % (18)	10.7 % (32)
13	Since the onset of my illness, I have become less interested in hearing about God or religion	300	18.7 % (56)	3.3 % (10)	78 % (234)
14	When I think of God, I feel agitated	300	25 % (75)	3.7 % (11)	71.3 % (214)
15	Because of my illness, I find it difficult to do *pūjā*	300	69.3 % (208)	4.3 % (13)	26.3 % (79)
16	My illness or pain is a punishment for wrong done by me	299	64.2 % (192)	14.4 % (43)	21.4 % (64)
17	Since the onset of my illness I am less concerned about doing what is good and right	300	43.3 % (130)	4.3 % (13)	52.3 % (157)
18	I blame myself for this illness	300	64.7 % (194)	11.7 % (35)	23.7 % (71)
19	Thinking about what will happen after death frightens me	300	52.3 % (157)	3.3 % (10)	44.3 % (133)
20	Due to my illness I can no longer believe in the existence of God	300	21 % (63)	5 % (15)	74 % (222)
21	I feel at peace	300	73.3 % (220)	5 % (15)	21.7 % (65)
22	I have a belief in God which gives me strength	300	87 % (261)	6 % (18)	7 % (21)
23	Praying or chanting makes me feel better	300	90.3 % (271)	4.3 % (13)	5.3 % (16)
24	Due to my illness I am not interested in doing *pūjā* or other religious rituals	300	36 % (108)	5 % (15)	59 % (177)
25	God has abandoned me	300	24.7 % (74)	7.7 % (23)	67.7 % (203)
26	My illness is a consequence of karma	299	74.9 % (224)	8.7 % (26)	16.4 % (49)
27	Due to my illness, I have lost faith in a higher benevolent power	300	22.3 % (67)	6 % (18)	71.7 % (215)
28	Since the onset of my illness I am wondering more often whether my decisions are good and right	300	46.3 % (139)	13 % (39)	40.7 % (122)
29	Others are to blame for my illness	300	8.7 % (26)	4.7 % (14)	86.7 % (260)
30	With this illness, God wants to punish me	299	66 % (198)	9 % (27)	24.7 % (74)
31	My life has no purpose	300	41.7 % (125)	6.7 % (20)	51.7 % (155)

Table 1 continued

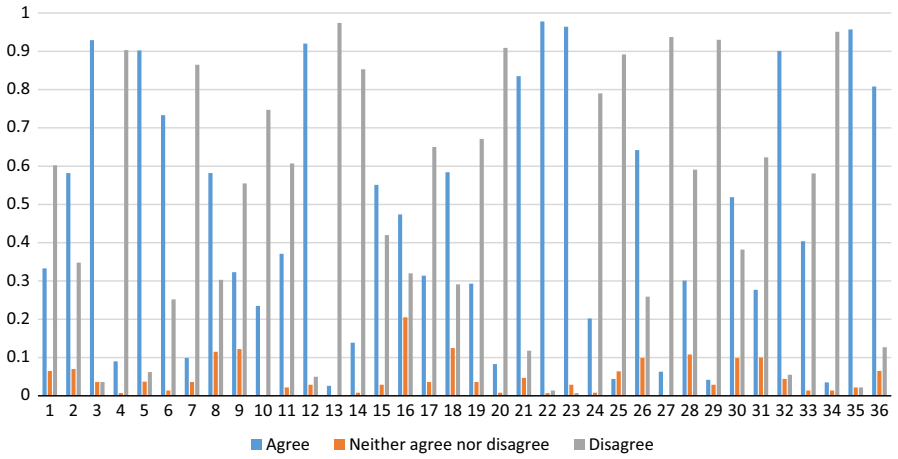
		n	Agree	Neither agree nor disagree	Disagree
32	I am grateful for my life	299	87 % (260)	5 % (15)	8 % (24)
33	I find it difficult to forgive myself for wrong I did	300	52 % (156)	3.3 % (10)	44.7 % (134)
34	Since the onset of my illness I have thought of changing my religion	300	5 % (15)	3.3 % (10)	91.7 % (275)
35	My faith in a higher power supports me in my illness	300	85 % (255)	7.3 % (22)	7.7 % (23)
36	This illness is my fate	300	85.3 % (256)	6.7 % (20)	8 % (24)

they considered themselves responsible for their disease and suffering through deeds that they had performed in this life or in a previous one. This shows that spirituality provided many patients with existential answers. In this context, most patients (85.3 %) called their illness their fate.

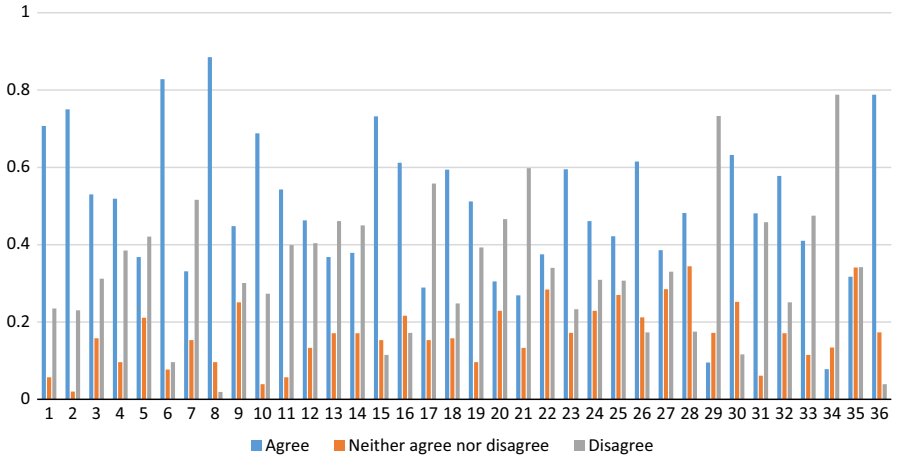
This does not mean that the patients found it easy to accept their condition. A large majority still kept wondering why this illness had happened to them (83.3 %), and they concluded that the illness was unfair (76.3 %). Moreover, the answers to the spirituality items also indicate that there was a substantial minority whose relationship with God or Ultimate Reality was highly convoluted. One in five patients (21 %) attested that they could no longer believe in the existence of God because of their illness or that they had lost faith in a higher benevolent power (22.3 %), and almost one in four (24.7 %) felt that God had somehow abandoned them.

In order to divide the patients into different spirituality groups, a latent class analysis was fitted, treating the manifest variables as nominal data. Each model with two to six latent clusters was fitted 500 times. The model with the best Bayesian information criterion (BIC) was selected. The final conditional item response probabilities for each of the clusters of the retained model can be found in the plots below. The numbers on the horizontal axis refer to the spirituality items in the questionnaire as mentioned in table one. For each item, the first bar indicates the conditional item response probability for agree, the second neither agree nor disagree, and the third disagree. The plots show whether members of each of the clusters were more likely to agree, disagree, or neither agree nor disagree with each of the ten statements. On the basis of these plots, the dominant characteristics of each cluster of respondents can be determined.

The first cluster (Graph 1) groups the patients who have trust in the future and God. Therefore, we have labelled patients in this cluster "trustful patients." 46.4 % of respondents belong to this cluster. Trust can be seen in their undiminished faith in God and the future. The illness has not affected their faith, as they have not become less interested in hearing or thinking about God or religion since the onset of their illness. They feel that God is with them and supports them. They seem to be convinced that God will also support them after death, because most of them do not wonder what will happen after death. They also are not afraid of the future or frightened by thinking about what will happen after death. This does not mean that they are entirely free of worries. Rather, they are worried about what will happen to their children or spouse later, but they are less likely to do so in comparison with patients in the other two clusters. Moreover, overall they feel at peace.



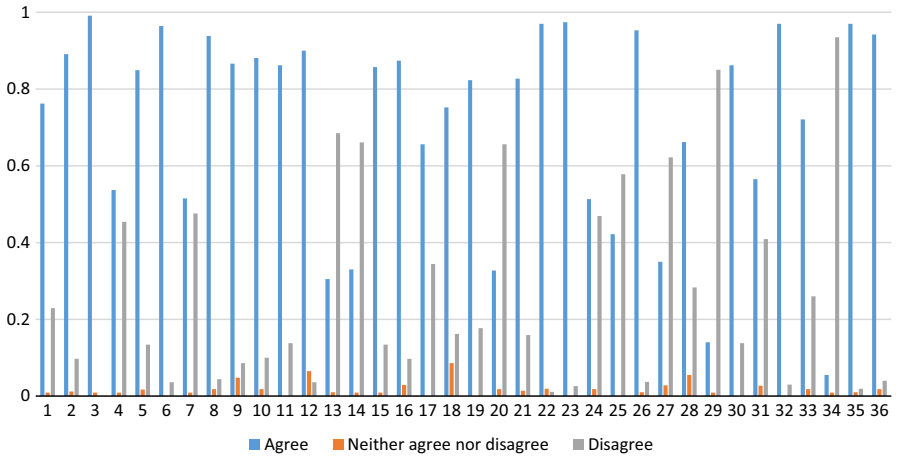
Graph 1 Conditional item response probabilities for cluster 1, trustful patients (46.4 %)



Graph 2 Conditional item response probabilities for cluster 2, spiritually distressed patients (17.4 %)

They find this peace in devotion (*pūjā*) to God. They seem to have accepted their condition, which they tend to see as a punishment for wrong they did, or even more as a consequence of karma and fate. Therefore, it is no surprise that patients in this cluster more often do not feel angry because of what is happening to them.

The second cluster (Graph 2) groups patients who can be labelled "spiritually distressed." 17.4 % of patients are in this cluster. Their spirituality is marred by anger, worry, and fear. Most of them feel angry about what is happening to them. They find their illness unfair and ask the question "Why?" Patients in this group see illness as a (divine) punishment for wrong committed by them, as karma, or fate. Consequentially, they blame themselves for the illness. But, these existential answers do not seem to give them peace of mind. They do not feel at peace, and most patients explicitly state this. They are worried



Graph 3 Conditional item response probabilities for cluster 3, patients clinging to divine support (36.2 %)

about what will happen to their spouse or children. They tend to wonder what will happen after death, and most are afraid of the future. Religious faith or faith in God does not seem to offer them much solace. Many of them have become less interested in thinking about God or religion since the onset of their illness. Many of them also do not believe that a higher power supports them. This is remarkable, as this belief is very strong in the two remaining clusters. There is a tendency among these patients to feel that God has abandoned them, and many of them agree that they have lost faith in a higher benevolent power due to their illness.

In the third cluster (Graph 3), we find 36.2 % of patients. They form an intermediate cluster in between the trustful attitude of the first cluster and the spiritual distress of the second. These patients display what at first seems to be contradictory feelings and emotions. They still have faith in God, and they long for His/Her support. Almost without exception, they are convinced that God is with them and supports them. They state that their belief in God gives them strength. This aligns with their perception of devotional activities as a source of peace, which makes them feel better. But at the same time, the reality of their illness forces them to ask profound existential questions that challenge their religious convictions. They wonder why the illness has happened to them, notwithstanding the fact that they believe that their illness or pain is a (divine) punishment, fate, or karma. They have a clear feeling of guilt. They feel lonely. They also experience anger because of their illness and find the disease unfair. Further, they worry about their own future and the future of their children or spouse. They wonder what will happen after death, too.

A Kruskal–Wallis test did not show a significant association between the spirituality clusters and age ($\chi^2 = 4.441$, $df = 2$, $p = .109$), nor did a Chi-squared test show an association with patients' own rating of their prognosis ($\chi^2 = 8.31$, $df = 4$, $p = .081$). However, Chi-squared tests did show significant associations for gender, marital status, educational level, and religious affiliation. These results are shown in Table 2. Women less often belong to the first cluster (trustful patients) and more often belong to the second (spiritually distressed patients) and third clusters (patients clinging to divine support) when compared to men. Not-married patients more often belong to the first (trustful patients) and second clusters (spiritually distressed patients) when compared to married patients. The

Table 2 Association of spirituality clusters with gender, marital status, educational level, and religious affiliation

Demographic variable	Spirituality clusters			Total	Test result
	Cluster 1: trustful patients	Cluster 2: spiritually distressed patients	Cluster 3: patients clinging to divine support		
Gender					
Women	38.5 % ($n = 57$)	20.3 % ($n = 30$)	41.2 % ($n = 61$)	100 % ($n = 148$)	$\chi^2 = 7.226$, $df = 2$, $p = .027$
Men	53.9 % ($n = 82$)	14.5 % ($n = 22$)	31.6 % ($n = 48$)	100 % ($n = 152$)	
Marital status					
Not-married patients	58,6 % ($n = 17$)	27.6 % ($n = 8$)	13.8 % ($n = 4$)	100 % ($n = 29$)	$\chi^2 = 7.226$, $df = 2$, $p = .024$
Married patients	45 % ($n = 122$)	16.2 % ($n = 44$)	38.7 % ($n = 105$)	100 % ($n = 271$)	
Educational level					
Uneducated	34.5 % ($n = 29$)	16.7 % ($n = 14$)	48.8 % ($n = 41$)	100 % ($n = 84$)	$\chi^2 = 25.811$, $df = 6$, $p < .001$
Until 10th	45.1 % ($n = 60$)	13.5 % ($n = 18$)	41.4 % ($n = 55$)	100 % ($n = 133$)	
Intermediate	57.1 % ($n = 20$)	22.9 % ($n = 8$)	20.0 % ($n = 7$)	100 % ($n = 35$)	
Graduate	63.8 % ($n = 30$)	25.5 % ($n = 12$)	10.6 % ($n = 5$)	100 % ($n = 47$)	
Religious affiliation					
Hindus	46.1 % ($n = 111$)	19.9 % ($n = 48$)	34.0 % ($n = 82$)	100 % ($n = 241$)	$\chi^2 = 6.117$, $df = 2$, $p = .047$
Non-Hindus	48.3 % ($n = 28$)	6.9 % ($n = 4$)	44.8 % ($n = 26$)	100 % ($n = 58$)	

more the patients have studied, the more likely they are to be in the first cluster (trustful patients). Patients who have studied less can more often be found in cluster 3 (patients clinging to divine support). Hindus are more often in cluster 2 (spiritually distressed patients) in comparison with non-Hindu patients, while the latter are more often in cluster 3 (patients clinging to divine support).

Further, a Kruskal–Wallis test showed that there was a statistically significant difference in pain scores between the different clusters ($\chi^2 = 16.098$, $df = 2$, $p < .001$, with a mean rank pain score of 131.33 for cluster 1, 184.32 for cluster 2, and 157.50 for cluster 3). Patients in cluster 2 (spiritually distressed patients) suffer from more severe pain, while patients in cluster 1 (trustful patients) suffer the least.

The multinomial logit model was used to assess whether the associations remain significant when we control for covariates. Gender, marital status, educational level, religious affiliation, and pain scores were put into this model. The McFadden's pseudo-R^2 coefficient for our model ($R^2 = .104$) suggests that our model fit is moderate. Table 3 shows the multinomial regression coefficients as odds ratios between reference category cluster 1 and clusters 2 and 3. A likelihood ratio test was performed and found to be significant for pain

Table 3 Multinomial logistic regression

	Cluster 2: spiritually distressed patients		Cluster 3: patients clinging to divine support	
	Odds ratio (95 % CI)	*p* value	Odds ratio (95 % CI)	*p* value
Pain score	1.349 (1.152–1.579)	<.001	1.181 (1.032–1.351)	.016
Gender (ref = female)				
Male	.511 (.252–1.037)	.063	.511 (.289–.906)	.022
Marital status (ref = married)				
Not-married (unmarried, widowed, divorced)	1.281 (.476–3.449)	.624	.112 (.118–1.250)	.112
Religion (ref = non-Hindu)				
Hindu	2.950 (.936–9.296)	.065	.706 (.455–1.706)	.706
Educational status (ref = postgraduate)				
Uneducated	1.848 (.328–10.422)	.487	.090 (.826–13.948)	.090
Less than class 7	1.519 (.255–9.038)	.646	.255 (.546–9.826)	.255
Until 10th	1.215 (.197–7.504)	.834	.118 (.745–13.515)	.118
Intermediate	1.690 (.276–10.343)	.570	.956 (.212–5.154)	.956
Undergraduate	1.743 (.290–10.464)	.544	.244 (.042–2.233)	.244

scores ($p < .001$), gender ($p = .034$), and educational level ($p < .006$), but not for marital status ($p = .146$) and religious affiliation ($p = .069$).

Discussion

The patients' answers to the individual spirituality items point to the contextual particularity of spirituality. Spirituality in India seems to be strongly determined by the Indian economic and religious context. This becomes clear when we look at those items to which most respondents (>70 %) agreed. These items typically had to do with belief in fate and karma, support from religion, *pūjā* (devotional practice), and worry about one's children and/or spouse. Belief in karma is an important aspect of Indian religiosity. It refers to the conviction that persons will have to experience the consequences of their deeds in this life or in a next life. This implies that if a person falls ill, this may very well be because he or she has committed a bad deed in this life or in a previous life (Bhattacharya 2004; Chaturvedi et al. 2014; Deshpande et al. 2005; Jagannathan and Juvva 2011). In our study, 74.9 % of patients agreed that their illness was a consequence of karma. In earlier studies, too, Indian palliative care patients have been found to believe in karma (Mehta 2011; Pahwa et al. 2005; Ramanakumar et al. 2005; Simha et al. 2013) and rebirth (Simha et al. 2013). Yet, among the studied patients, agreement with the statement that the illness was fate was even more frequent (85.3 %). The frequency of the conviction that illness is a person's fate can be explained by the fact that "fate" is a broad concept that can be accepted by patients belonging to different religions in India. For Hindus, fate may be largely similar to karma. But also for many Muslims, who constitute a substantial religious

minority in India, and who may see everything, including illness, as willed by God (Van den Branden and Broeckaert 2008), "fate" can be an acceptable category.

These findings already illustrate the lasting impact of religion on the patients' spirituality. While traditional religiosity has declined in the West, in India most people are often explicit about their belief in God. This is the same in Indian palliative care, where 98 % of palliative care patients stated that they believe in God (Mishra et al. 2010). Many Indian patients have been found to believe that God has the power to cure their illness and will effectively do so (Bottorff et al. 2007; Howard et al. 2007; Jagannathan and Juvva 2009). This observation helps us understand the large agreement with statements indicating belief in divine support. 90.4 % agreed that "Praying or chanting makes me feel better," 88.3 % "God is with me," 87 % "I have a belief in God which gives me strength," 85 % "My faith in a higher power supports me in my illness," 83.3 % "*Pūjā* is a source of peace for me," and 78.9 % "There is some higher power that supports me."

Thus, we can see a continuing influence of Indian religiosity on spirituality in palliative care in India. This shows the contextual nature of spirituality. Therefore, researchers should be careful when they use questionnaires and scales that have been developed in other parts of the world. Although such tools can sometimes be helpful, they may fail to capture specific aspects of spirituality that are of special importance in other regions. This may be particularly true for spirituality questionnaires and scales that have been developed in Western countries and apply a secular interpretation of spirituality (Bradshaw 1996; Paley 2008; Walter 2002). Such scales may have limited value in the Indian palliative care context, where religion, and more specifically Indian religiosity, still plays a decisive role in patients' spirituality.

However, the particularity of spirituality among Indian palliative care patients is not restricted to the influence of Indian religiosity. The large number of patients in our sample who had had limited or no education suggests that many of the patients belong to the lower socioeconomic strata of Indian society. Poverty in India is still a pervasive reality with 21.9 % of the population living below India's national poverty line (UNESCAP-SSWA 2015). The economic reality of poverty is an aspect that has to be considered while studying spirituality in Indian palliative care, as it may determine how people spiritually experience their disease. This is also what the patients' answers seem to indicate. 72.3 % worried about what would happen to their children and/or spouse in case they did not get better. For patients who know that their family will be left with very limited financial means after their death, this may be a greater worry than for patients who are better-off. The interaction of socioeconomic context, as well as culture and religion, with spirituality is clearly attested by the latent class analysis and the clusters' associations with demographic variables and pain scores.

In the multinomial logit model, the clusters were found to be significantly associated with pain scores, gender, and educational level. Patients who had completed intermediate education or obtained at least a graduate degree were more likely to display spiritual trust (cluster 1), while patients who had studied less were more often clinging to divine support (cluster 3). This seems to be in line with the observations of Jagannathan and Juvva (2009), who found that less educated cancer patients in India were more likely to have a limited understanding of their disease and to despair more easily after diagnosis. In our survey, there were no questions specifically inquiring about the patients' economic condition. Yet, we may assume that, generally, patients who have enjoyed less education will also be economically less successful in later life. For Indian patients with limited financial means, financial constraints may complicate coping with a disease. In India, health insurance is still uncommon, and prolonged treatment for an illness, such as cancer, may literally ruin a

family. This may create feelings of insecurity. Patients may not only worry about their own future, but they may also wonder how their family is going to manage later. Such worries can impact spiritual trust, which includes such insecurity about the future.

Our observation that spiritually distressed patients (cluster 2) were more prone to severe pain, while trustful patients (cluster 1) experienced less physical pain, seems to confirm the importance of certain kinds of spirituality as a coping mechanism for pain (Wachholtz and Pearce 2009; Wachholtz et al. 2007). Nevertheless, not all studies that have assessed spiritual and physical pain have found an association between the two. In this regard, the study of Mako et al. (2006) that was conducted in a palliative care hospital in New York City is of particular relevance. Like the present study, Mako and her colleagues studied palliative care cancer patients, but they did not find a correlation between physical pain and intensity of spiritual pain, whereas the present study did observe a significant association between spirituality and physical pain. More research regarding the possible association between spiritual and physical pain is required. Yet, we have to remark that the questionnaire that was used to collect the data that we analyzed in the present study was specifically designed for the studied population (Bhatnagar et al. 2016), which may therefore be considered an adequate culturally appropriate measure of spirituality. This may not always be the case in other studies. As a consequence, spirituality may not always be appropriately measured, and an association between physical and spiritual pain may not be detected.

Our finding that women are less likely than men to be trustful (cluster 1) and more likely to be spiritually distressed (cluster 2) and clinging to divine support (cluster 3) may also be explained by the above-mentioned importance of fear for the future, both for themselves and their family, in the third cluster. Traditionally, women are seen as the central providers of care in Indian families. This can help us understand why Indian women lose spiritual trust when confronted with a severe illness. They may fear that they may no longer be able to fulfill their caring role in the family. This may make them worry more about their family's future, and it may also make them wonder whether their life still has meaning without that role. Also, the WHOQOL HIV Group (2004) found in an international study, which included samples in India, that women fear the future more than men.

Patients who display such signs of spiritual distress may benefit from spiritual care. A close look at the profiles of the three spirituality clusters reveals that a very substantial part of the studied cancer patients is in need of spiritual counselling. Patients who may not immediately need spiritual counselling are most likely to be found in the first cluster. This cluster was the largest cluster (46.4 % of patients) and was labelled "trustful" patients. Patients in this group will not immediately require much attention from the palliative care team concerning spirituality. They display trust in God and the future. They are able to manage their worries, because they feel at peace. And they seem to have found answers to existential questions, which they find somewhat acceptable. The second cluster is entirely different from the first. Patients in this cluster, 17.4 % or well over one-sixth of all patients, are clearly spiritually distressed and need spiritual counselling. They experience anger and are worried and fearful. They do not feel at peace. They have turned away from religion over the course of their illness. Also, belief in a supportive God no longer appeals to them. As we can assume that these patients are severely distressed by their spiritual issues and concerns, these should be addressed by someone with specific training in the provision of spiritual care to this group. The third cluster, grouping 36.2 % of patients, is an intermediate group, which was called patients clinging to divine support. These patients believe that God will help them, and they derive support from religion. Nevertheless, they also experience anger, guilt, loneliness, and fear for the future. Patients in this group may also

benefit from spiritual care, although the need may not be as urgent as for the second group. Since patients in clusters two and three may benefit from spiritual care, we can conclude that over half of the studied population (53.6 %) should receive spiritual counselling.

While assessing these observations, the study's limitations should be taken into consideration. The data that were used for this study were collected in only one hospital in Northern India. It is difficult to make out to what extent our findings can be generalized to palliative care populations elsewhere in India. The studied pain clinic exclusively caters to cancer patients, and all sampled patients were suffering from cancer. Other patients with palliative care needs, such as HIV/AIDS patients, may experience spiritual distress differently. Future studies on spirituality in palliative care should try to include larger samples from more diverse palliative care programs. We may also have underestimated the prevalence of spiritual distress in Indian palliative care patients. While collecting the data, patients who were showing signs of extreme pain were excluded for ethical reasons (Bhatnagar et al. 2016). Among the studied patients, the mean pain score was 3.22 on a scale of 10. In our study, we observed a highly significant association between physical pain and spiritual distress. Thus, we can assume that spiritual distress has been underreported. Lastly, the questionnaire did not allow us to assess differences in distress levels among patients. To this end, specific spiritual distress scales are required. Development of such scales could be the object of future research.

Conclusion

Our study has shown that a substantial share of palliative care patients in India may be in need of spiritual counselling. Unfortunately, at present, research, education, and training in spirituality in Indian palliative care have been very limited. There are only a few studies that specifically focus on spirituality in Indian palliative care. Spirituality education for palliative care physicians, nurses, and counsellors in India hardly ever goes beyond a very basic introductory level, and it generally relies on Western models and interpretations of spirituality, which, as we have argued, do not seem adequate for the Indian context. Professionals, such as chaplains, with extensive training in the provision of spiritual care to terminally ill patients are most often not available. In these circumstances, much spiritual suffering remains untreated. Because of this, many patients in India will remain unsatisfied with the care they receive. Therefore, there is an urgent need for more research, education, and training in spirituality in Indian palliative care.

While setting up scientific studies and designing training programs in spirituality, it is important to consider the particularity of spirituality in Indian palliative care. Our study has made clear that aspects of Indian religiosity, such as karma, fate, and *pūjā*, exert a large influence on how patients spiritually experience their disease. Such aspects may not be neglected in studies and education in spirituality in Indian palliative care. Moreover, the contextual particularity of spirituality in India goes beyond mere religiosity. Our results pointed to a strong association between socioeconomic situation and spirituality. The association between spirituality, educational background, and economic condition would require more study in Indian palliative care. In Indian palliative care, this association is of great importance given the precarious economic condition of many patients. It has to be added, however, that many palliative care programs in India already do pay attention to this aspect by also assessing patients' and their relatives' financial needs and assisting them wherever they can.

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Compliance with Ethical Standards

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References

Banerjee, B., Vadiraj, H. S., Ram, A., Rao, R., Jayapal, M., Gopinath, K. S., et al. (2007). Effects of an integrated yoga program in modulating psychological stress and radiation-induced genotoxic stress in breast cancer patients undergoing radiotherapy. *Integrative Cancer Therapies, 6*(3), 242–250.

Bhatnagar, S., Noble, S., Chaturvedi, S. K., & Gielen, J. (2016). Development and psychometric assessment of a spirituality questionnaire for Indian Palliative Care Patients. *Indian Journal of Palliative Care, 22*(1), 9–18.

Bhattacharya, G. (2004). Health care seeking for HIV/AIDS among South Asians in the United States. *Health and Social Work, 29*(2), 106–115.

Bottorff, J. L., Grewal, S. K., Balneaves, L. G., Naidu, P., Johnson, J. L., & Sawhney, R. (2007). Punjabi women's stories of breast cancer symptoms: Gulti (lumps), bumps, and Darad (pain). *Cancer Nursing, 30*(4), E36–E45.

Bradshaw, A. (1996). The spiritual dimension of hospice. The secularization of an ideal. *Social Science and Medicine, 43*(3), 409–419.

Caldeira, S., Carvalho, E. C., & Vieira, M. (2013). Spiritual distress-proposing a new definition and defining characteristics. *International Journal of Nursing Knowledge, 24*(2), 77–84.

Chandra, P. S., Gandhi, C., Satishchandra, P., Kamat, A., Desai, A., Ravi, V., & Kumar, M. (2006). Quality of life in HIV subtype C infection among asymptomatic subjects and its association with CD4 counts and viral loads: A study from South India. *Quality of Life Research, 15*(10), 1597–1605.

Chaturvedi, S. K., Strohschein, F. J., Saraf, G., & Loiselle, C. G. (2014). Communication in cancer care: psycho-social, interactional, and cultural issues. A general overview and the example of India. *Frontiers in Psychology, 5*, 1332.

Clark, D. (2001). Religion, medicine, and community in the early origins of St. Christopher's Hospice. *Journal of Palliative Medicine, 4*(3), 353–360.

Cobb, M., Dowrick, C., & Lloyd-Williams, M. (2012). What can we learn about the spiritual needs of palliative care patients from the research literature? *Journal of Pain and Symptom Management, 43*(6), 1105–1119.

Deshpande, O., Reid, M. C., & Rao, A. S. (2005). Attitudes of Asian-Indian Hindus toward end-of-life care. *Journal of the American Geriatrics Society, 53*(1), 131–135.

EAPC. (2015). EAPC taskforce on spiritual care in palliative care. Retrieved from http://www.eapcnet.eu/Themes/Clinicalcare/Spiritualcareinpalliativecare.aspx.

El Nawawi, N. M., Balboni, M. J., & Balboni, T. A. (2012). Palliative care and spiritual care: the crucial role of spiritual care in the care of patients with advanced illness. *Current Opinion in Supportive and Palliative Care, 6*(2), 269–274.

Gielen, J. (2014). Why does spirituality matter in end of life care. In R. Das & S. Nayak (Eds.), *Concepts of palliative care* (pp. 72–80). Cuttack: A.K. Mishra Publishers.

Gielen, J., Bhatnagar, S., & Chaturvedi, S. K. (2015). Spirituality as an ethical challenge in Indian palliative care: A systematic review. *Palliative and Supportive Care*. doi:10.1017/S147895151500125X.

Howard, A. F., Bottorff, J. L., Balneaves, L. G., & Grewal, S. K. (2007). Punjabi immigrant women's breast cancer stories. *Journal of Immigrant and Minority Health, 9*(4), 269–279.

Jagannathan, A., & Juvva, S. (2009). Life after cancer in India: coping with side effects and cancer pain. *Journal of Psychosocial Oncology, 27*(3), 344–360.

Jagannathan, A., & Juvva, S. (2011). Palliative care: An Indian perspective. In T. Altilio & S. Otis-Green (Eds.), *Oxford textbook of palliative social work* (pp. 561–565). New York, NY: Oxford University Press.

Kandasamy, A., Chaturvedi, S. K., & Desai, G. (2011). Spirituality, distress, depression, anxiety, and quality of life in patients with advanced cancer. *Indian Journal of Cancer, 48*(1), 55–59.

Kudla, D., Kujur, J., Tigga, S., Tirkey, P., Rai, P., & Fegg, M. J. (2015). Meaning in life experience at the end of life: Validation of the Hindi version of the Schedule for Meaning in Life Evaluation and a cross-

cultural comparison between Indian and German palliative care patients. *Journal of Pain and Symptom Management, 49*(1), 79–88.
Lewis, S., Salins, N., Rao, M. R., & Kadam, A. (2014). Spiritual well-being and its influence on fatigue in patients undergoing active cancer directed treatment: A correlational study. *Journal of Cancer Research and Therapeutics, 10*(3), 676–680.
Linzer, D. A., & Lewis, J. (2011). poLCA: An R package for polytomous variable latent class analysis. *Journal of Statistical Software, 42*(10), 1–29.
Linzer, D. A., & Lewis, J. (2013). poLCA: Polytomous variable latent class analysis. Retrieved from http://dlinzer.github.com/poLCA.
Mako, C., Galek, K., & Poppito, S. R. (2006). Spiritual pain among patients with advanced cancer in palliative care. *Journal of Palliative Medicine, 9*(5), 1106–1113.
McDermott, E., Selman, L., Wright, M., & Clark, D. (2008). Hospice and palliative care development in India. A multi-method review of services and experiences. *Journal of Pain and Symptom Management, 35*(6), 583–593.
Mehta, J. B. (2011). Spirituality and medicine: Dying with grace. *Southern Medical Journal, 104*(4), 294.
Mishra, S., Bhatnagar, S., Philip, F. A., Singhal, V., Singh Rana, S. P., Upadhyay, S. P., & Chauhan, G. (2010). Psychosocial concerns in patients with advanced cancer: An observational study at regional cancer centre, India. *American Journal of Hospice and Palliative Medicine, 27*(5), 316–319.
Pahwa, M., Babu, N., & Bhatnagar, S. (2005). Fighting cancer is half the battle… living life is the other half. *Journal of Cancer Research and Therapeutics, 1*(2), 98–102.
Paley, J. (2008). Spirituality and secularization: Nursing and the sociology of religion. *Journal of Clinical Nursing, 17*(2), 175–186.
Puchalski, C., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., et al. (2009). Improving the quality of spiritual care as a dimension of palliative care: The report of the Consensus Conference. *Journal of Palliative Medicine, 12*(10), 885–904.
Rajagopal, M. R., & Palat, G. (2002). Kerala, India: status of cancer pain relief and palliative care. *Journal of Pain and Symptom Management, 24*(2), 191–193.
Ramanakumar, A. V., Balakrishna, Y., & Ramarao, G. (2005). Coping mechanisms among long-term survivors of breast and cervical cancers in Mumbai, India. *Asian Pacific Journal of Cancer Prevention, 6*(2), 189–194.
Selman, L., & Higginson, I. J. (2010). 'A softening of edges': A comparison of yoga classes at palliative care services in New Delhi and London. *International Journal of Palliative Nursing, 16*(11), 548–554.
Shanmugasundaram, S., Chapman, Y., & O'Connor, M. (2006). Development of palliative care in India: An overview. *International Journal of Nursing Practice, 12*(4), 241–246.
Simha, S., Noble, S., & Chaturvedi, S. K. (2013). Spiritual concerns in hindu cancer patients undergoing palliative care: A qualitative study. *Indian Journal of Palliative Care, 19*(2), 99–105.
UNESCAP-SSWA. (2015). *India and the MDGs: Towards a sustainable future for all*: United Nations.
Van den Branden, S., & Broeckaert, B. (2008). Medication and God at interplay: End-of-life decision-making in practicing male Moroccan migrants living in Antwerp, Flanders, Belgium. In J. E. Brockopp & T. Eich (Eds.), *Muslim medical ethics: From theory to practice* (pp. 194–208). Columbia: University of South Carolina Press.
Wachholtz, A. B., & Pearce, M. J. (2009). Does spirituality as a coping mechanism help or hinder coping with chronic pain? *Current Pain and Headache Reports, 13*(2), 127–132.
Wachholtz, A. B., Pearce, M. J., & Koenig, H. (2007). Exploring the relationship between spirituality, coping, and pain. *Journal of Behavioral Medicine, 30*(4), 311–318.
Walter, T. (2002). Spirituality in palliative care: Opportunity or burden? *Palliative Medicine, 16*(2), 133–139.
WHOQOL HIV Group. (2004). WHOQOL-HIV for quality of life assessment among people living with HIV and AIDS: Results from the field test. *AIDS Care, 16*(7), 882–889.
Wright, M., George, R., & Mingins, R. (2004). Exploring the meaning of spiritual care in the Indian context: Findings from a survey and interviews. *Progress in Palliative Care, 12*(5), 221–226.