

Estimation of Palliative Care Need in the Urban Community of Puducherry

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Abstract

Context: The coverage of palliative care services is inadequate in India. Data on number of people needing palliative care and disease conditions needing palliative care needs to be estimated prior to planning of service in any area. **Aims:** To estimate the prevalence of need of palliative care in an urban area of Puducherry. **Settings and Design:** Exploratory cross-sectional study conducted in two areas, Senthamarainagar and Thiruvalluvarnagar having about 500 households each in Muthialpet area in urban Puducherry. **Materials and Methods:** All residents were interviewed using a structured questionnaire containing sociodemographic details, information regarding chronic illness and a screening tool to identify people in need of palliative care. **Statistical Analysis:** Variables such as sociodemographic characteristics were expressed in percentages. The main outcome variable, the number of people in need of palliative care was expressed in the prevalence percentages. **Results:** A total of 3554 individuals were surveyed in 1004 households. A period prevalence of need of palliative care in this community was 6.1/1000 population. The prevalence among those aged ≥ 15 years was 8/1000 population. The mean age of people requiring palliative care was 62 years. The most common disease condition in need of palliative care was old age-related weakness (41%). Most of them were women (17/22) and from lower socioeconomic class (6/22). **Conclusions:** Around 6/1000 population was identified to be in need of palliative care. The prevalence was highest among the elderly women, low socioeconomic class, widowed, those with less education, and those suffering from age-related weakness.

Keywords: Conditions, need, palliative care, Puducherry, services, urban

INTRODUCTION

There is an increasing recognition of unmet need to provide palliative care services globally. Globally, in the year 2011, around 29 million people died of diseases requiring palliative care.^[1] In India with around 1.2 billion people, every year more than 9.8 million people are dying and most of them die with unbearable pain and with other psychosocial distress. It is estimated that around 60% of them would benefit from palliative care.^[2] According to the World Health Organization Global Health estimates 2011, around 54.6 million deaths occurred globally, and among those deaths 66% were due to noncommunicable diseases, 25% were due to communicable, maternal, perinatal and nutritional causes, and 9% were due to injuries. Among these diseases, noncommunicable diseases were the major one requiring palliative care services in addition to other chronic conditions such as HIV/AIDS and drug-resistant tuberculosis.^[1] Trend in India is similar to the global trend of disease mortality. In India, the major contributions to diseases requiring palliative care are from

noncommunicable diseases that account for 53% of all deaths in India.^[3] There is an increasing proportion of elderly in the Indian population. The 2001 census showed that there were 72 million elderly in India (7%) and in 2011 census showed an increase to 76 million (7.5%) and it is expected to reach 12.17% by 2026.^[4] In future, it is expected that the highest number of patients requiring palliative care will be from the terminally ill elderly patients. All these chronic, life-limiting diseases make the patients suffer from pain, other symptoms, and psychosocial distress which decrease their quality of life significantly and these illnesses not only affect the patients but also affect their family or caregivers in physical and psychosocial aspects. Hence, a holistic approach of care, i.e., palliative care is essential to take care of all these issues of patients and their families.

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According to the World Health Organization (WHO), palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment, and treatment of pain and other problems, physical, psychosocial, and spiritual.^[1] Palliative care is not only for cancer patients but is also extended to people with HIV, severe kidney disease, heart failure, end-stage lung disease, progressive neurological diseases, and other life-limiting illnesses.^[5] The coverage of palliative care services is very sparse and inadequate in the country. According to recent estimate, only < 2% of those who need have access to any type of palliative care.^[2] In India, currently, about 908 palliative care centers are providing palliative care either through home care or on outpatient basis or inpatient service. Among them, 841 centers are in Kerala, so it can be observed that majority of the palliative care services are available only in one state, and there are some states in the country without a single center for providing palliative care services.^[4]

There are studies done globally and in different countries for estimating the number of people in need of palliative care.^[1,6] Among these studies, most of them have provided estimation based on hospital data of chronic end-stage patients. Community-based studies for assessing the people in need of palliative care are very scarce worldwide. In India, even after thorough literature search through electronic media, studies on estimation of people requiring palliative care could not be found.

Puducherry, with a population of around 12 lakhs,^[7] has well-developed and widely accessible health-care facilities. However, palliative care is in rudimentary phase available in only in few tertiary care centers, not integrated with the health system of Puducherry. The number of people who might need palliative care, disease conditions requiring palliative care and various aspects of their needs are not known. Hence, a baseline assessment is needed in these aspects to estimate the basic palliative care needs in Puducherry. Estimating the needs is a critical step as it will provide a basis for planning services. Nearly 75% of the population of Puducherry is in urban areas.^[7] Therefore, this study was conducted to identify the people and estimate the prevalence of need of palliative care in the urban community of Puducherry.

MATERIALS AND METHODS

Study design and setting

An exploratory cross-sectional study was conducted in two areas, Senthamarainagar and Thiruvalluvarnagar having about 500 households each, under Muthialpet Primary Health Centre (PHC), an urban PHC in Puducherry. This area was selected purposively after discussion with the Deputy Director of Public Health, Government of Puducherry as being representative of the urban population of Puducherry.

Study duration

The study was conducted between January 2013 to January 2014.

Study population and study tool

All the residents of the selected areas were included in the study, and the visitors to those areas were excluded from the study. They were studied using a structured questionnaire.

Data collection and analysis

Sociodemographic details (age, gender, education, occupation, religion, caste, type of house, and socioeconomic status) and information regarding chronic illness were collected from all study participants. For considering marital status as per the legal age of marriage proposed by “The Prohibition of Child Marriage Act 2006,” males <21 years and females <18 years were excluded from the study. For analyzing education status, <5 years were excluded as per structure adopted in the National Family Health Survey-3 survey.

For considering occupational status, individuals <14 years were excluded from the study. Socioeconomic status was assessed using modified Kuppaswamy socioeconomic scale 2012. To identify people in need of palliative care, all participants were screened with a screening tool consisting of three questions. This screening tool was obtained through personal communication with the consultant working for a nongovernmental organization in the field of palliative care in Hyderabad, which conducted a similar community-based survey.^[8] The questions were finalized after consultation with experts in the field of palliative care. The questions are as follows:

1. Is there anyone in your family who is bedridden?
2. Is there anyone in your family who is unable to go to work because of a physical illness?
3. Is there anyone in your family who is not well and needs help to look after his/her activity of daily living?

If the answer to any of the above-mentioned questions were yes, participants were asked whether it was because he/she was suffering from any of the following illnesses (heart disease, lung disease, cancer, kidney disease, neurological/brain disease, arthritis, diabetes, hypertension, and congenital disease) for more than 3 months in the last 1 year. If they had an illness involving any of these conditions, they were identified as in need of palliative care [Figure 1].

Data were entered in Excel sheet and were analyzed using IBM Corp. Released 2011. IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp. Statistical tests were not applied as the number of people in need of palliative care was less. The study variables such as sociodemographic characteristics were expressed in percentages. The main outcome variable, the number of people in need of palliative care was expressed in prevalence percentages.

RESULTS

Totally, 3554 individuals were surveyed in 1004 households. Among the 1004 households surveyed, highest proportion (37%)

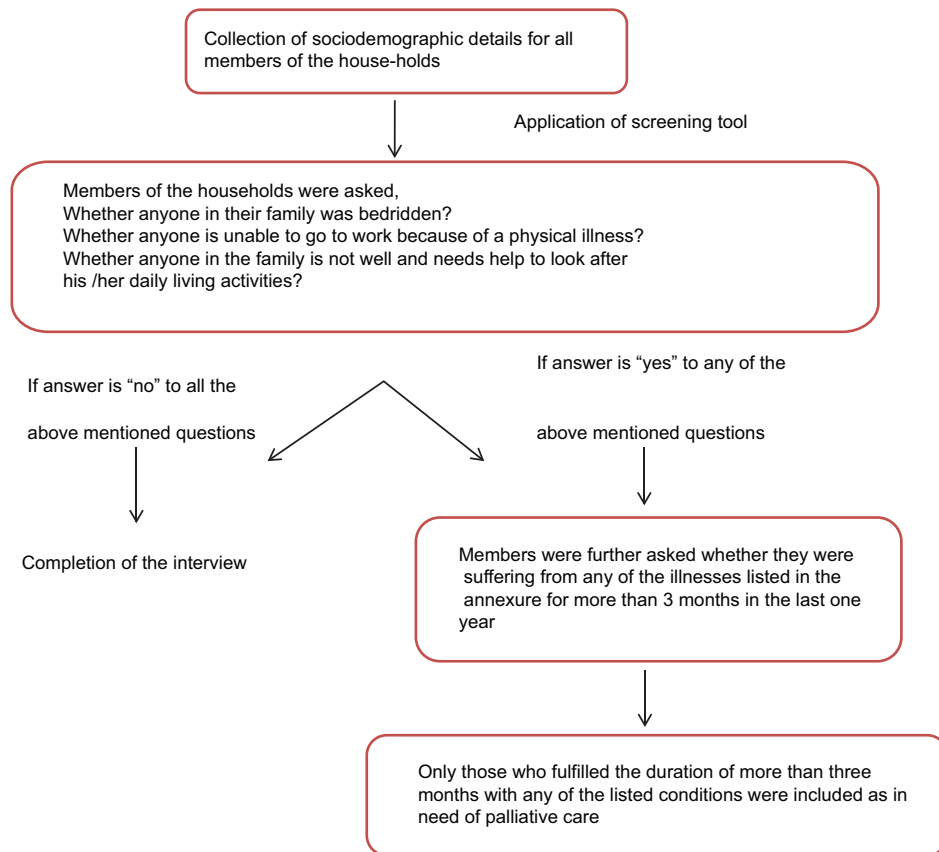


Figure 1: Procedure of household interview.

were in 20–39 years. Elderly age group constituted 11% (7% in 60–69 years and 4% in ≥ 70 years). More than half were women (53%).

Higher proportion of women was in lower class (82.5%). Majority 691 (69%) lived in pucca houses, followed by semipucca 273 (27%), and kutchha forty (4%) houses. Higher proportion of women was living in kutchha houses. More than three-fourth (79%) were nuclear families, and 21% were joint families. Higher proportion of men was from nuclear families, and higher proportion of women was from joint families. Majority 828 (83%) followed Hinduism, 132 (13%) followed Christianity, and 44 (4%) followed Islam. More than half 526 (52.4%) belonged to Backward Class (BC), followed by 437 (43.5%) from Scheduled Caste (SC).

Of the 3554 individuals, 2629 individuals were included for analyzing marital status and among them more than half (66%) were married, 11% were widowed, and 1% were separated. Higher proportion of women was in widowed (93%) and separated (72%) categories. As per the educational status, highest proportion (22.5%) was in high school category, 8.5% were illiterates, and only 2.4% were in professional level of education. Among the 2897 individuals above 14 years, highest proportion (18%) were involved in elementary occupations, followed by 7% in craft and related trade works.

The highest proportion was from the lower middle class (37.2%), followed by the upper lower (30.9%), and very less proportion from the upper (5%) and lower (2%) classes.

Among the surveyed 3554 individuals, 22 people were identified to be in need of palliative care. A period prevalence (22/3554) of 6.1/1000 was obtained.

Number of people requiring palliative care:

- Number of households covered = 1004
- Total population in 1004 households = 3554
- People identified in need of palliative care = 22.

Period prevalence per 1000 = $22 = 6.1/3554/1000$

- In <15 years, no one was identified to be in need of palliative care
- In ≥ 15 years - prevalence was 8/1000 population
 - Among males, it was 4/1000
 - Among females, it was 11/1000.
- Mean age of people requiring palliative care - 62 years
 - For males - 56 years
 - For females - 64 years.

Table 1 shows the age and gender distribution of the individuals requiring palliative care. As there were none below the age of 20 years requiring palliative care, the table shows the distribution for people aged more than 20 years ($n = 2606$). A higher proportion of people requiring palliative care was

from the elderly age group (59%) when compared with 40–59 years (32%) and 20–39 (9%). Mean age requiring palliative care was 62 years, 64 years, and 56 years among females and males, respectively. Age-wise prevalence per 1000 shows the need was more among the elderly (82.27) age group followed by 40–49 years (9.8). Of the people requiring palliative care more than three-fourth (77%) was women, more so in the older age group.

The most common disease condition in need of palliative care identified from the present study was old age-related weakness (41%). Next to age-related weakness, the other common conditions observed were chronic heart disease (18.5%), paralysis due to cerebrovascular accident (13.5%) postpolio residual paralysis, psychosis following head injury, cancer esophagus, chronic kidney disease, mild mental retardation, and filariasis leg [Table 2].

Sociodemographic characteristics of people requiring palliative care were as follows: [Table 3]

Housing characteristics

Of the 22 people requiring palliative care, 14 were residing in pucca houses, six in semi-pucca houses, and two in kutcha houses, but the prevalence of people in need of palliative care was highest in the kutcha houses (20/1000 vs. 5.6/1000 and 6/1000 in pucca and semi-pucca houses, respectively).

Family type

Overall, greater proportion of people requiring palliative care was in joint (13/22) compared to nuclear (9/22) families.

Religion

The majority (17/22) were Hindus followed by five Christians, and the distribution was almost equal between both genders. However, the prevalence was higher among Christians (10/1000) than among Hindus (6/1000).

Caste

Among the 22 people in need of palliative care, 15 belonged to SC and seven belong to BC with a higher prevalence in SC category (9/1000) versus (4/1000) in BC category.

Marital status

More than half (13/22) of those requiring palliative care were widowed. A higher proportion of widowed and separated

people were in need of palliative care, 45/1000 and 40/1000, respectively.

Educational status

Among the 22, the prevalence of palliative care need was highest in the illiterate group (29/1000).

Employment status

At the time of the study, all were unemployed. Before the onset of their illness, 11 (50%) were unskilled workers, nine (41%) were unemployed, and two (9%) were skilled workers. Among the unemployed, all were elderly females and they were not contributing to the income generating activities of the family.

Socioeconomic status

Higher number (8/22) were from lower middle class followed by six in lower class, and the prevalence of palliative care need was highest in the lower socioeconomic class (95/1000).

DISCUSSION

In this study in urban Puducherry, we found the period prevalence of palliative care needs to be 6.1/1000 population, which is higher than the estimates of 377 out of 1 lakh population, corresponding to a prevalence of around 4/1000 population by Global Atlas of palliative care.^[1] Another community-based survey using the same screening tool as ours conducted by pain relief and palliative care society, Hyderabad in Dameragidda village of Mandal Chevella, Rangareddy district have reported a very high prevalence of people in need of palliative care. They found 129/1000 population, approximately 9% were in need of some form of palliative care and chronic pain services.^[8] The difference in the prevalence may be attributed to differences in settings. Our study was conducted in urban Puducherry, which has very good health infrastructure and has the highest per capita health expenditure in the country. Therefore, the health status of the population is better as shown by the good health indicators. Better overall health status might be a reason for lesser need of palliative care. This and the other reasons for the difference need to be explored.

Studies done in other parts of the world, with better health status of the population have lower prevalence of people in

Table 1: Age and gender distribution of people in need of palliative care (n=22)

Age in years	Males		Females		Total population	Age-wise prevalence of people in need of palliative care (n/1000)
	Total	Number requiring palliative care	Total	People requiring palliative care		
20-29	322	-	370	1	692	1 (1.44)
30-39	318	-	337	1	655	1 (1.5)
40-49	244	2	262	3	506	5 (9.8)
50-59	190	2	184	-	374	2 (5.34)
60-69	105	-	135	3	240	3 (12.5)
≥70	53	1	86	9	139	10 (71.9)
Total	1232	5	1374	17	2606	22 (8.4)

Table 2: Disease conditions of people requiring palliative care (n=22)

Disease conditions	Male (n)	Female (n)	Total, n (%)
Age-related weakness	-	9	9 (41)
Chronic heart disease	1	3	4 (18.5)
Paralysis due to cerebrovascular accident	2	1	3 (13.5)
Postpolio residual paralysis	-	1	1 (4.5)
Cancer esophagus	-	1	1 (4.5)
Chronic kidney disease	1	-	1 (4.5)
Psychosis following head injury	1	-	1 (4.5)
Mild mental retardation	-	1	1 (4.5)
Filariasis (left) leg	-	1	1 (4.5)
Total	5 (23)	17 (77)	22 (100)

Table 3: Sociodemographic profiles of people in need of palliative care (n=22)

Sociodemographic characteristics	Total number of individuals (n)	People requiring palliative care (n/1000)		
		Female (n)	Male (n)	Total, n (%)
Housing				
Kutchha	98	2	0	2 (20.4)
Semi-pucca	946	5	1	6 (6.3)
Pucca	2510	10	4	14 (5.6)
Total	3554	17	5	22 (6.1)
Family type				
Nuclear	2599	5	4	9 (3.5)
Joint	995	12	1	13 (13)
Total	3554	17	5	22 (6.1)
Religion				
Hindu	2915	13	4	17 (6)
Christian	491	4	1	5 (10)
Total	3406	17	5	22 (6.4)
Caste				
Other backward class	1803	5	2	7 (4)
Scheduled caste	1628	12	3	15 (9)
Total	3431	17	5	22 (6.4)
Marital status				
Never married	572	3	0	3 (5.2)
Currently married	1742	1	4	5 (3)
Separated	25	0	1	1 (40)
Widowed	290	13	0	13 (45)
Total	2629	17	5	22 (8.4)
Educational status				
High school (9-10)	743	2	2	4 (5.4)
Middle school (6-8)	527	3	3	6 (11.4)
Primary school (1-5)	540	4	0	4 (7.4)
Illiterate	279	8	0	8 (29)
Total	2089	17	5	22 (10.5)
Socioeconomic status				
Upper middle (16-25)	889	3	0	3 (3.4)
Lower middle (11-15)	1390	6	2	8 (6)
Upper lower (5-10)	1053	4	1	5 (5)
Lower (0-4)	63	4	2	6 (95)
Total	3395	17	5	22 (6.5)

need of palliative care. In Spain, the prevalence was about 422/1 lakh, nearly 4/1000 in need of palliative care.^[9]

Other studies worldwide are among patients in hospitals and need of palliative care is expected to be higher among them as compared to community-based surveys. The prevalence was much higher (1.5%) among the patients of chronic disease in selected health-care facilities of Spain.^[10] Gott *et al.* found even higher prevalence (19.8%) of people in need of palliative care among the inpatients of a hospital in New Zealand.^[6] Palliative care council of New Zealand based on hospital admission and mortality statistics on a national basis has reported a very high prevalence of 41.8% people in need of palliative care among those who aged ≥ 20 years.^[11] This could be because of the difference in the methodologies adopted.

The present study showed a higher proportion of people requiring palliative care from the elderly age group (59%). WHO also reports a higher proportion (66%) of palliative care need among elderly age group of more than 60 years.^[12] Similarly, Global atlas of palliative care reported a higher proportion (69%) of need among the elderly.^[1] Gott *et al.* found the prevalence of need to be 72% in the elderly age group.^[6] The reasons for the higher proportion of need among elderly age group could be because of the increasing life expectancy and rising burden of noncommunicable diseases.

In the present study, higher proportion of need of palliative care was among females (77%). This could be because of the higher life expectancy among the women. Life expectancy of women in Urban Puducherry was found to be 71 years compared to 66.9 years among males.^[13] Gómez-Batiste *et al.* also found a higher proportion of need among females (61.4%)^[10] in Spain and also the National Alliance for Caregiving, United States, which identified higher proportion of need (62%) among females.^[14]

Among conditions requiring palliative care identified in this present study, old age-related weakness (41%) was the highest. Gómez-Batiste *et al.* also found that the common condition requiring palliative care was advanced frailty (31.3%).^[10] National Alliance for Caregiving also found that the common condition in need of palliative care in the United States was old age-related illness (12%).^[14]

Studies from the hospital settings give contrasting results. These cannot be compared to our findings as only the severe cases and those who have access reach the hospitals. Gott *et al.* in New Zealand identified the common condition to be in need of palliative care as malignancies (47%) and a very less proportion from old age-related frailty (5.1%).^[6] Similarly, Raghavan *et al.* in India found that malignancy (93%) was the common disease in need of palliative care and a very less proportion (7%) from other causes including general debility due to old age.^[15] Global Atlas of palliative care, released by the WHO and Worldwide Palliative Care Alliance, based on mortality statistics mentioned the most common disease to be in need of palliative care among adults as cardiovascular diseases (38.5%).^[1] Similar to our study, Gott *et al.* have

reported chronic heart disease (11.1%) as the second common condition. The other conditions identified in their study were renal disease (8.1%), chronic obstructive pulmonary disease (5.1%), and frailty (5.1%).^[6] Next to cardiovascular diseases, the other common conditions mentioned in the Global atlas of palliative care were cancer (34%), chronic respiratory diseases (10.3%), HIV/AIDS (5.7%), and diabetes (4.5%). WHO has mentioned the common conditions to be in need as Alzheimer and other dementias, cardiovascular diseases, Parkinson's disease, rheumatoid arthritis, chronic obstructive pulmonary diseases, diabetes, nephritis, nephrosis, and cancer.^[1] Raghavan *et al.* also mentioned the common conditions other than malignancies as dementia, cerebrovascular diseases, peripheral vascular diseases, coronary artery diseases, Parkinson's disease, nonhealing wounds due to infected hip prosthesis, osteoporosis with multiple fractures, bed-ridden patients due to old age general debility.^[15] Elderly people who suffer from general debility due to old age may not be able to access hospitals or centers providing palliative care. Problems related to old age are often ignored by the family members and not considered to require care in the hospital. Therefore, old age does not feature in the studies done in hospital settings. However, their needs cannot be ignored as this condition is important in terms of numbers for providing community-based palliative care services.

Of the other factors related to health, housing is an important factor that can affect the health outcome of the patient. Improper housing conditions can lead to physical health problems. In our study, majority were from pucca (64%), followed by kutcha (9%) houses. However, it was observed that although more number of people in this study was from pucca houses, most of these were very small, single room houses, with inadequate facilities, and improper living conditions. Many of these were rented houses. An observational study done by Jameson in South Africa reported the problems of poor housing among 50% of the people in need of palliative care.^[16] Type of family is most important in terms of providing support to the patient. Most (59%) people in need of palliative care in our study were from joint families and 41% from nuclear family. We observed that patients from joint family perceived less physical and psychological stress when compared to people from nuclear family. In joint family, there are many people to take care of the person; however in nuclear families, the problem observed was the presence of only one caregiver for providing care to the patient, so it affected the family in many ways in terms of physical, psychological, and financial issues. Palliative care services can be easily provided to those with good support in the family.

Among the people in need of palliative care in our study, majority were widowed (59%), followed by married (23%), and unmarried (13.5%). The higher prevalence observed among the widowed was because of the higher number of elderly women in the present study, and the common disease condition observed among them was old age-related weakness. Similar to this, report released by National Alliance

for caregiving, the United States mentioned the highest proportion (37%) of need among widowed followed by married (26%) and unmarried (27%).^[14] However, in contrast our findings, studies done by Rainbird *et al.*^[17] and Strada *et al.*^[18] reported that 72% and 50%, respectively of those who were in need of palliative care were married. Connell *et al.* too reported a high proportion of married (63%) among those in need of palliative care.^[19] Lower levels of education have been found among people in need of palliative care. In our study, 36.3% were illiterates and very less proportion had completed high school education (18.2%). A study from New Delhi, India, too showed high proportion (21%) of need among illiterates.^[20] Jameson found that only 10% had completed high school level of education.^[16] In our study, 36% were from lower middle class, and 27% were from lower class. The prevalence among lower socioeconomic group in this study is 95/1000 compared to 6/1000 in the lower middle and 5/1000 upper lower class. Other studies in India showed similar findings. In Delhi, 59% of people in need were from low socioeconomic status followed by 36% from the middle class.^[20] Rajmohan and Kumar also showed a higher proportion (82%) of need from low socioeconomic status.^[21]

This study had some limitations. To identify the people in need of palliative care, the screening tool was administered to all members of the family. However, among few families, the information of all the members of the family was collected from any one of the members of the family as it was not possible to interview all the members of the family during the time of visit. Other limitations can be chronic illnesses and comorbidities may not be diagnosed among the general population, which may be a reason for the lower prevalence of these conditions among people in need of palliative care in this study.

CONCLUSIONS

This was an exploratory study done among the residents of two selected areas under Muthialpet PHC. Around 6/1000 population was identified to have palliative care need. The prevalence was highest among the elderly women, low socioeconomic class, widowed, those with less education, and those having age-related illness.

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Conflicts of interest

There are no conflicts of interest.

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