Original Article

Attitude of Volunteers in a Community-Based Palliative Care Program in Puducherry: A Cross-sectional Descriptive Study

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Abstract

Objectives: Since 2015, volunteers are being trained in Palliative care at Puducherry to meet the increasing demand. Hence, this study aimed in assessing volunteer's attitude towards palliative care which will help in promoting the quality of services.

Methods: A cross-sectional descriptive study was done among volunteers working for palliative care in and around Puducherry. All the 60 volunteers who were available during September-October 2018 were included in the study. A pre-tested, semi-structured questionnaire was administered to capture the socio-demography and attitude. Continuous variables were summarized as median (IQR) and categorical variables were expressed as frequency and percentages.

Results: The study found 36.7 % of the volunteers were in the age group of 31-40 years, 76.7% were females and 78.3% married. About 10% were illiterate, and 35% were daily wage workers. In the domain, attitude towards the patient and the services provided, depression and grief in patients were the two areas that had unfavourable attitude. About 75% positive attitude toward self, however, majority felt caring for a dying person is depressing. The domain on communication with the patient revealed, though 91% felt they have an obligation to tell patients and family members when death is imminent, 78% felt it is discouraging to talk about death to a dying person.

Conclusions: Presently volunteers are coming from only lower socio-economic strata of the society. There's a need to have greater representation of all sections among volunteers. Enhanced training covering mental health aspects of self and patients needs to be provided. There is a need to advocate for providing more emphasis on community-based services than relying on hospital settings, including enhancing caregivers/family members' capacities in delivering the care.

Key Words: social care, terminal care, supportive care, home care, bereavement

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Introduction

The WHO report (2018) states, at least 40 million people need palliative care each year and only 14% of them are currently receivingit.[1,2] Need for end-of-life care is increasing all over the world with lots of people dying every year without proper care with a predicted rise from 14% in 2002 to 42%by 2030.[3] The Palliative care is well integrated into their health-care systems only in 20 countries. Most palliative care services are provided in high-income countries, whereas almost 80% of the need is in low and middle-income countries.[4] This creates an alarming increase in demand for palliative health care in these settings. In India, less than 1% of its 1.2 billion population have access to palliative care. Kerala, a state in South India, having 3% of India's general population, excels interms of achieving coverage of palliative care.[5] Presently, there are 908 palliative care service providers (home care/ outpatient basis/ inpatient service) in India. Around 840 of these centres are present in Kerala which indicates that palliative care services are virtually non-existent in the rest of India.[5,6]

Palliative care volunteers, are the heart of home-based care, making services accessible to patients in need of palliative care but not able to visit palliative care clinics in hospitals, thus improving their quality of life and finally helping them die with dignity.[6] Despite its benefits, home-based palliative care has not been adopted in most parts of the world. Adequate focus on health at the end of life is also required to accomplish the goal of universal health coverage. As the need for palliative care is not yet met in resource constrained countries like India, volunteers can play an important role in expanding these services to those in need. The implementation of a palliative care programme through volunteers is in place and training has been started in Puducherry, since 2015. An intensive literature search revealed that there are limited studies done on volunteers working for palliative care in India and no such studies are done yet in Puducherry. Addressing the experiences and attitude of the volunteers is important in improving their work experience to keep them motivated and thus improving the quality of care provided by them. Hence, this study aimed at knowing their profile, experiences and attitude towards palliative care.

Methodology

A descriptive cross-sectional study was conducted in Puducherry, a Union Territory (UT) in South India. This UT has nine medical colleges in its vicinity, of which three are providing home based palliative care. Also, there are two Non-Governmental Organizations (NGOs) Sanjeevan and SCOPE providing the same. Volunteers are part of the care provided by these NGOs only. Most of these volunteers worked without any remuneration, six only were receiving some payment for this service. We included all the 60 palliative care volunteers working in these two organisations at the time this study was conducted. Together they cater to around 2000 patients in need of palliative care. A team comprising of a doctor, a nurse and a social worker along with a volunteer visit the patients once in every 2 months. Volunteers make regular visits at least once a week to ensure their wellness and in case of emergencies, the palliative care team is informed and immediate attention is given.

As the number of volunteers working for palliative care is minimal, we included all the volunteers who were available during the study period (September-October 2018). After explaining the purpose of the study and obtaining an informed consent in the local language of the participants, a total of 60 volunteers were administered a pre tested, semi-structured questionnaire which was framed in English and translated to the native language (Tamil) with validation for language and face validation for the content by experts in the field of palliative care. Questionnaire attempted to capture their socio-demography and attitude towards palliative care. Items assessing attitude were under three domains; attitude of the volunteers towards patients and the services provided with nine items, attitude towards their own self while providing care with 12 items, and attitude towards communication with the patients with four items. This questionnaire was adopted from the available literature with modifications done by experts providing palliative care services and training.[7-9] Attitude was captured using statements on the subject under the domain with responses in a five-point Likert scale (strongly agree, agree, neutral, disagree, strongly disagree) which was later transformed into a three-point Likert scale (agree, neutral and disagree) during the time of analysis.

The data was captured using a mobile application EpiCollect5 Version 1.1.4 and exported as Comma Separated Value (CSV) file and imported to Statistical Package of Social Sciences (SPSS) Version 17.0 for analysis. Continuous variables like years of experience as palliative care volunteers and duration since they were aware of palliative care was summarized as median and inter quartile range. Categorical variables like age group, gender, education, occupation, Socio-economic status were summarized as frequencies and percentages. Attitude was summarized as favourable, neutral and unfavourable for each item individually. For the positive worded statements, agree and strongly agree responses were considered favourable and for the negatively worded statements, disagree and strongly disagree were considered favourable.

Results

A total of 60 volunteers were found eligible during the study period and all were approached for the study. There was no refusal and all 60 patients were included in the study. The median (IQR) age of participants was 36 (28 - 48) years.

Demographic characteristics of registered volunteers under a home-based palliative care programme in Puducherry (**Table 1**) shows, 36.7% of the population were in the age group of 31-40 years and more than three fourth (76.7%) of them were female. Majority (78.3%) of them were married with equal proportions (50%) from urban and rural areas. One out of ten did not have any formal education and about one third (35%) of them were daily wage labourers. The median (IQR) family income in INR of the volunteers was 12000/ month (10000 - 15000) and the median (IQR) number of members in their families and children were 4 (4-5) and 2 (1-2) respectively; majority belonging to a nuclear family. About 40% of the families belong to class II category of BG Prasad scale 2018 of socio-economic status.

Median (IQR) duration of experience as palliative care volunteers under a home-based palliative care programme in Puducherry **(Table 2)** was 3 (2-4) years; however, the median (IQR) period since they were aware of palliative care was 2 (1-3) years. More than half (58%) of the participants reported having heard about it for the first time from doctors. One-fourth of the participants had someone in the family or friends working as a volunteer.

For seven out of the nine statements on patients and palliative care services, 70% - 90% of the participants had the favourable attitude. The two areas where lower proportion of volunteers had favourable attitude were depression and grief in patients; 85% felt that *"depression is not treatable in patients at the end of life" and* 90% perceived that *"there is little that can be done to ease the grief of the patient"*. (**Table 3)**

Regarding their own self while providing care, 60-90% of the participants had favourable attitude for nine out of the twelve statements. Among the aspects with unfavourable attitude, about 40% of the volunteers felt that *"caring for patients who are dying is depressing"*; 16.6% said *"I would be uncomfortable if I entered the room of a terminally ill person and found him/ her crying"* and 45% said, *"I feel guilty after the death of a patient"*. **(Table 4)**

In the domain on communication, more than 50% of the participants had favourable attitude for two out of the four statements. Unfavorable attitude was found in higher proportion of participants for statements like *"Talking about death tends to make patients at the end of life more discouraged"* with 78% agreeing and though lesser, still 28.3% felt that *"It is easier to talk about death and dying with someone of my own cultural or religious group than with someone who is not"*. **(Table 5)**

Table 1: Socio-demographic characteristics of registered volunteers under a home-based palliative care programme in Puducherry. (N = 60)

Variable	Category	Frequency	Percentage
Age group (in years)	18-30	18	30.0
	31-40	22	36.7
	41-50	10	16.7
	More than 50	10	16.7
Gender	Male	14	23.3
	Female	46	76.7
Residence	Urban	30	50.0
	Rural	30	50.0
Marital status	Married	47	78.3
	Unmarried	10	16.7
	Widowed	03	05.0
Educational status	Illiterate	6	10.0
	Primary	13	21.7
	Middle	9	15.0
	High	9	15.0
	Higher secondary	12	20.0
	Graduate	11	18.3
Occupational status	Unemployed	9	15.0
	Daily waged	21	35.0
	Government sector	2	3.0
	Private sector	17	28.0
	Business	10	17.0
	Student	1	2.0
Socio-Economic Status (in INR[#])[*]	Class I (≤ 6574)	02	3.3
	Class II (387- 6573)	24	40.0
	Class III (1972- 3286)	18	30.0
	Class IV (986 - 1971)	13	21.7
	Class V (≥985)	03	05.0
Family type	Nuclear	48	80.0
	Joint	12	20.0

[*] *BG Prasad scale 2018*

[#] *INR – Indian Rupees*

Table 2: Distribution of participants in regards to the duration since they were aware of Palliative care and experience as a palliative care volunteer under a home-based palliative care programme in Puducherry. (N = 60)

Variable	Median (inyears)	Inter-Quartile Range (inyears)
Duration since aware of palliative care	3	2 – 4
Duration of experience as palliative care volunteers	2	1 – 3

Source of first information about palliative care*	Frequency	Percentage
Doctor	35	58
NGO	12	20
Nurse	4	7
Volunteers	7	12
Teachers	2	3

**Multiple options are possible*

Table 3: Attitude of volunteers towards the patient and services they provide in a home-based palliative care programme in Puducherry. (N=60)

S.no	Statement*	Attitude of volunteers		
		Favourable n (%)	Neutral n (%)	Unfavourable n (%)
1	Palliative care team brings real benefits to patients at the end of life	54 (90.0)	4 (6.7)	2 (3.3)
2	Psychological suffering can be as severe as physical suffering	55 (91.7)	3 (5.0)	2 (3.3)
3	Depression is normal in patients at the end of life	53 (88.3)	5 (8.3)	2 (3.3)
4	Depression is not treatable in patients at the end of life	9 (15.0)	14 (23.3)	37 (61.7)
5	The palliative care team has a responsibility to help patients prepare for death	56 (93.3)	1 (1.7)	3 (5.0)
6	There is little that can be done to ease the grief of the patient	6 (10.0)	10 (16.7)	44 (73.3)
7	We have a responsibility to provide bereavement care to the patient's family after the death of the patient	57 (95.0)	1 (1.7)	2 (3.3)
8	I feel helpless when I cannot assist in the families, I visit because of limited resources	50 (83.3)	7 (11.7)	3 (5.0)
9	Death is not the worst thing that can happen to a person	43 (71.7)	7 (11.7)	10 (16.7)

**Statement number 4 and 6 are negatively worded and options disagree and strongly disagree are considered to be a favourable response while agree and strongly agree are considered favourable for other statements.*

Table 4: Attitude of volunteers towards their own self while providing home-based palliative care in Puducherry. (N=60)

S.no	Statement*	Attitude of Volunteers		
		Favourable n (%)	Neutral n (%)	Unfavourable n (%)
1	Caring for patients who are dying is depressing	24 (40.0)	8 (13.3)	28 (46.7)
2	I feel guilty after the death of a patient	27 (45.0)	11 (18.3)	22 (36.7)

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3	I dread having to deal with the emotional distress of family members	38 (63.3)	7 (11.7)	15 (25.0)
4	My social life has suffered because of volunteering	46 (76.6)	1 (1.7)	13 (21.7)
5	I cannot do what I want because of volunteering	51 (85.0)	7 (11.7)	2 (3.3)
6	I feel mentally exhausted as a result of volunteering for the terminally ill	45 (75.0)	4 (6.7)	11 (18.3)
7	I feel physically exhausted as a result of volunteering for the terminally ill	49 (81.7)	6 (10.0)	5 (8.3)
8	I worry about getting an infection from my patient.	51 (85.0)	6 (10.0)	3 (5.0)
9	I feel like giving up this role of volunteering	58 (96.7)	0 (0.0)	2 (3.3)
10	I am afraid to become friends with chronically sick and dying patients	42 (70.0)	4 (6.7)	14 (23.3)
11	I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	10 (16.6)	13 (21.7)	37 (61.7)
12	I feel comfortable to share the difficulties faced by a patient at the end of life or their family members with my colleagues or documenting discussion them in the record	42 (70.0)	11 (18.3)	7 (11.7)

[*] *Statement number12 is positively worded and options agree and strongly agree are considered to be a favourable response while disagree and strongly disagree are considered favourable for other statements.*

Table 5: Attitude of volunteers on communicating with the patients receiving home-based palliative care in Puducherry. (N=60)

S.no	Statement[*]	Attitude of Volunteers		
		Favourable n (%)	Neutral n (%)	Unfavourable n (%)
1	The Palliative care team has an obligation to tell patients and family members when death is imminent	55 (91.7)	2 (3.3)	3 (5.0)
2	Talking about death tends to make patients at the end of life more discouraged	12 (20.0)	1 (1.7)	47 (78.3)
3	It is easier to talk about death and dying with someone of my own cultural or religious group than with someone who is not	17 (28.3)	8 (13.3)	35 (58.4)
4	Suggested procedures or treatments sometimes give patients/family false hope	31 (51.6)	4 (6.7)	25 (41.7)

[*] *Statement number1and 3are positively worded and options agree and strongly agree are considered to be a favourable response while disagree and strongly disagree are considered favourable for other statements*

Discussion

This study was first to explore the socio-demography and attitude of palliative care volunteers in an Indian setting. The median age (IQR) of the study participants was 36 (28-48) years with 36.7% of them in the category of 31- 40 years of age, similar to other studies conducted by Goss, Hayghe, Freeman, and others where majority of the people were in the age group of 35-54 years.[10] Middle aged people are more likely to be caregivers in their own families and understand the importance of palliative care, thus willing to take up the role of volunteers. Few had taken up this as a profession for an earning, many of the volunteers belonging to the lower socio-economic classes. Whereas the survey conducted by Victoria's health department showed that the average age of the volunteers was 64 years.[11]The younger age group of volunteers in India may be due to the lower life expectancy in India of 69 years. So, people in that age group seem more likely to seek care rather than being a volunteer.

Majority of our study participants were females (76.6%), married (83.3%) and living in a nuclear family (80%) which is similar to the findings reported in other studies as well.[10,11] Nearly 10% of the study participants were illiterate, more than one-third (35%) were daily wage workers and belonged to class II category (40%) of modified BG Prasad scale 2018. This shows that volunteering for palliative care is not considered important by people in upper socio-economic classes in our society even though the need for palliative care is pervasive across all sections of the society. People from the lower strata are more empathetic and for some it is also an avenue for some income. This was very different from the studies conducted in other countries where those with higher education, employment and income were more likely to volunteer.

Overall, about two-third of the participants had a favourable attitude towards patients and the services provided; and also, towards what they felt while providing services. However, there was a mixed opinion for the attitude towards communication.

Attitude of the volunteers towards patients and the services provided

Among the participants only 10% felt that depression can be treated at the end of life and only 15% felt that anything can be done to ease the grief of the patients which means that majority were not trained adequately to consider depression as a treatable condition at the end of life. This would have led them to ignore depression in such patients. For the statements related to depression only 10%-15% of the participants had a favourable attitude, unlike other study that was done in Canada.[7] Ideally, palliative care aims at increasing the quality of mental health at the end of life which these volunteers may not have been able to do. Training of volunteers in mental health aspects of patients in need of palliative care is tougher, so also provision of mental health services to the patients, requiring more dedicated time and efforts both in training and service.

Our study had 83.3% of the participants accepting *"I feel helpless when I cannot assist in the families I visit because of limited resources"*, indicating that the volunteers are not provided with adequate resources to support the families of patients in need of palliative care. This could be one of the obstacles in rendering quality care to the patients which in-turn have had led to discontentment among the service receivers. In a study *Mashau et al.* from South Africa reported that only 29% of the participants agreed to the same, which is a huge difference from our setting and could be attributed to the integration of palliative care with the health system and the educational system in South Africa, which is still at infancy in India. It may also be due to the limited resources provided for palliative care in our setting.[9]

About 71.1% of the study participants agreed to the statement *"death is not the worst thing that can happen to a person"*. This gives us an idea that the volunteers consider that everyone has to experience this phase and death is a natural phenomenon and people tend to suffer when they live with the disease. Thereby, reducing the suffering and agony of patients at the end stages of life striving to give a peaceful and dignified death. Studies conducted in Ethiopia and Lubumbashi among palliative care nurses found around 33% of the nurses agreed to the above-mentioned statement. The contrasting results from our study may be due to the greater acceptance of death among the volunteers here, which may be due to the witnessing of suffering in these patients and considering death a release or a more spiritual inclination.[8,11]

Domain 2: Attitude towards their own self while providing care

This domain had 12 statements. The study result showed a mixed response to the statements *"I feel guilty after the death of a patient"* and *"Caring for patients who are dying is depressing"*. About 62% agreed to the statement *"I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying"*. The reason could be the emotional attachment of the volunteers towards the patients or lack of resilience required to provide care for terminally ill people. Since they are uncomfortable or feel depressed on seeing patients crying, they might tend to reduce the number of volunteering hours for the patient with terminal illness thus compromising with the services provided. Other studiesshowed that nearly 93% of the participants disagreed for the first statement, which ensued due to the higher field exposure and better experience. Nearly 71% agreed to the second and 56.5% to the latter statement which is more or less similar to our study results where a higher proportion of the participants gave an unfavourable response.[7,8]

This study showed a better attitude for some of the other statements like *"I feel physically/ mentally exhausted as a result of volunteering for the terminally ill"*, *"I worry about getting infection from my patient"* and *"I feel like giving up this role of volunteering"* with 81.7%, 75%, 85%, and 96.7% disagreeing, meaning a favourable attitude towards providing palliative care. This clearly shows their willingness to volunteer for the needy in-spite of the obstacles they come across. Hence, with adequate training and constant support, they would be able to serve in a better way. Other similar study from South Africa had only 14.1%, 33%, 23.2%, and 58% volunteers with favourable attitude in these areas respectively.[9] This variance may have occurred because majority of their study participants had to travel more than 20 kilometers a day and there are higher chances of them getting exhausted while the volunteers in our study cater to the nearby population which is comparatively much lesser distance. It can also be due to the severity and the type of patients they see.

For all the other statements, our study results are similar to all other studieswith higher proportion of people having a favourable response.[7-9,13]

Domain 3: Attitude towards communicating with the patients

The domain constituted of four statements. Our study shows that 91.7% of the volunteers thought *"The Palliative care team has an obligation to tell patients and family members when death is imminent"*. This implies that the volunteers are clear about their roles and responsibilities and hence, can prepare the patient for dignified death and the family, for the death of the resident. Most of the participants from a study in Canada also had similarly high proportion of volunteers, 82% agreeing to the statement.[7]

In our study 20% and 28.3 % volunteers agreed that *"Talking about death tends to make patients at the end of life more discouraged"*, *"It is easier to talk about death and dying with someone of my own cultural or religious group than with someone who is not" respectively*. A discussion regarding end-of-life or death is still considered as taboo in India and most of the people do not ponder about this issue. But studies from other setting have shown that 47.3% and 60.8% had disagreed for the same.[7]This may be because of the cultural differences that exist between countries regarding discussion on matters related to death.

There was a mixed response to the statement *"Suggested procedures or treatments sometimes give patients/family false hope"* which had a more or less similar finding with other studies.[9] Probably, this can be as a result of the communication gap between the health care providers and the patient.

Strengths and limitations:

Our study had certain strengths as we covered all the volunteers available during the study period without any sampling, thus removing selection bias. As no standard questionnaire is available to assess the attitude of the palliative care volunteers, we tailored a questionnaire to suit the Indian population taking references from the existing literature. There is however, a limitation as there could have been social desirability bias with participants responding what they ought to say rather than what they actually felt. Self-administered questionnaire could have led to desirability bias which is a limitation.

Conclusion

Presently volunteers are coming from only lower socio-economic strata of the society. There's a need to have greater representation of all sections while enrolment of new volunteers as the need for palliative care is pervasive across the society. Identifying volunteers from general population and student communities would help us strengthen community-based palliative care services through volunteers. Enhanced training with regards to the factors that have been identified with poor attitude like "treating depression at the end-of-life" and "considering death as a taboo" will enable us in provision of quality care.

To improve palliative care services in India, palliative care should be integrated at all levels of healthcare, with a particular emphasis on primary care. Provide outpatient clinics for specialized care without hospital admission, hospice or hospital inpatient care for intense assistance, and home-based care with trained family caregivers and routine professional visits. Prioritise community-based services by strengthening the capacity of caregivers via training, creating community support networks, and expanding accessibility, especially in rural regions. Create mobile clinics and use telemedicine to conduct consultations from a distance. These steps will ensure palliative care, which is compassionate, all-inclusive, and easily accessible throughout the country.

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Conflict of Interest: The authors have no conflicts of interest to declare.

Key Message box		
Questions	**Clinical**	**Research**
What was already known?	NA	Volunteers bridge the health system and patients
	NA	Palliative care volunteers helpto expand services in resource-limited settings
What are the new findings?	NA	The majorityare female, middle-aged,daily-wagelabourers
	NA	Two-thirds of the participants hada favourable attitude
What is their significance?	NA	Training in handling the depression and grief of patients is required
	NA	Target young adults to volunteer to meet increasing demands

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