

Awareness and Attitudes of Primary Caregivers toward End-of-Life Care in Advanced Cancer Patients: A Cross-Sectional Study

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Abstract

Introduction: Awareness of end-of-life care (EOLC) has been at grass root level in our country. The caregivers are clueless about the concept of comfort care and that terminally ill cancer patients need care at home rather than the paraphernalia of the hospital ward. The basic aim of the study was to assess the awareness of the EOLC in the caregivers of the advanced cancer patients. **Methods:** After Ethics Committee approval, this prospective cross-sectional observational study was conducted among primary caregivers of patients receiving palliative care for advanced cancer. The primary caregiver was identified and written informed consent was obtained. The questionnaire for assessing awareness and attitudes of primary caregivers toward EOLC in advanced cancer patients was prepared and validated. The standardized study questionnaire was completed by the primary caregiver assisted by the researcher. The categorical data were analyzed using Fisher's exact test and Chi-square tests. The intergroup correlation was done using the Chi-square and nonparametric tests. **Results:** The results showed that only mere 26% of caregivers were aware of the term palliative care. The female population was more knowledgeable about EOLC, with 68% of them willing to initiate the same. The rural population was more willing to adopt palliative care (47%) and was more receptive about discontinuing aggressive definitive therapy. **Conclusion:** We conclude that the awareness about EOLC remains poor in caregiver if patients with advanced cancer in spite of good awareness of the disease. The consequences of the outcome of disease, EOLC understanding, futility for definitive care, acceptability, and understanding of palliative care lacked in most of the caregivers.

Keywords: Attitude, awareness, cancer, caregiver, end-of-life care, palliative care, terminal

INTRODUCTION

Palliative care aims at improving the quality of life (QOL) not only of patients with chronic diseases but also of their caregivers. End-of-life care (EOLC) is an extension of the continuum of palliative care which goes a step further to provide symptom relief and compassionate care to patients with terminal illnesses. EOLC is about quality of dying, and it abrogates the concept of an agonizing death surrounded by the paraphernalia of critical care.^[1] The concept of palliative care has many prime dimensions including medical, psychological, social, ethical, and legal. EOLC broadens the spectrum of palliation and includes "comfort care," "terminal care," and "bereavement support."^[2] Medical futility as one of the principles of medical ethics needs to be incorporated effectively in medical management, especially of patients with terminal illnesses.^[3]

The appropriate modality and timing of integrating EOLC discussion with family members is a gray zone that needs further studies. The awareness about EOLC remains at ignorance level, and attitudes of caregivers toward advanced cancer patients appear unacceptable. Appropriate awareness and acceptable attitude of primary caregivers of patients with advanced cancer would benefit the community at large with better acceptability for EOLC. However, the data related to the level of understanding,

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awareness, and attitude are scarce in the Indian population. The primary objective of this cross-sectional study was to assess the awareness and attitude of primary caregivers toward EOLC in advanced cancer patients. The secondary objective was to correlate various parameters with awareness of EOLC in primary caregivers of advanced cancer patients. Understanding these parameters shall be useful for various barriers and limitations for effective implementation of EOLC.

METHODS

After obtaining Institutional Ethics Committee approval (vide letter no IEC-447/04.08.2017, RP-28/2017 dated August 25, 2017), this prospective cross-sectional observational study was conducted among primary caregivers of patients receiving palliative care for advanced cancer at a tertiary care cancer. The study was registered at Clinical Trials Registry-India (CTRI) (Website URL-<http://ctri.nic.in>) vide CTRI/2017/09/009647. Primary caregivers of patients suffering from advanced cancer who have been denied curative treatment including chemotherapy, radiotherapy, and/or surgery and receiving only palliative/supportive care were recruited for the study. The primary caregiver was identified by inquiring the attendants or the patient and the person who stays with the patient for providing care and support to the patient. The primary caregiver was explained about the study protocol and written informed consent was obtained. The standardized study questionnaire was completed by the primary caregiver assisted by the researcher.

Study tool

Questionnaire for assessing awareness and attitudes of primary caregivers toward end-of-life care in advanced cancer patients

A standardized questionnaire was prepared by a literature review for content inclusion, selection of relevant items, and finally, preparation of the instrument. A thorough literature review was done by researcher from various search engines including PubMed/Medline, Scopus, and Cochrane using keywords related to awareness and attitude of caregivers toward EOLC for their advanced cancer patients. The relevant question set was chosen from this search and was shared with five subject experts. The experts were asked to comment on this question set with regard to ambiguity, relevance, comprehensiveness, and clarity of the items. The opinion for any missing items was also sought from these experts. Based on the inputs, the questionnaire was modified. In case of any discrepancy, the decision was taken by discussion among the researchers. The modified questionnaire was shared with five laypersons and five caregivers of advanced cancer patients for feedback with regard to clarity and understanding of each item mentioned in it. The feedback was analyzed and questionnaire revised accordingly. This final tool was translated to Hindi using to and fro translation method.

Finally, the operational instrument was constructed after the final generated items were refined and organized in the proper

format and sequence. The tool so developed was translated in Hindi using to and fro language conversion for its validity.

The questionnaire comprises the following sections:

- Part A included demographic details of the patient as per the hospital record. It included the age of the patient, diagnosis, and treatment received
- Part B included demographic details of the primary caregiver. It included age, relation with the patient, gender, marital status, educational status, habitat, occupation, income, details of the family, and social strata
- Part C included parameters related to awareness and attitude toward EOLC among primary caregivers of patients. It has subsections related to assessment of knowledge about disease, awareness about EOLC, awareness about comfort care, and assessment of financial support and issues. Caregivers were assessed regarding the knowledge of primary disease, time of diagnosis, treatment received, and its outcome. Caregivers were inquired details about course of the cancer including progression into advanced stage whether the patient is amenable to further palliative therapy or is refractory to further treatment. Whether the patient has already been started on palliative treatment and his/her desire to decline further definitive therapy was elicited from caregivers. Caregivers were assessed for baseline knowledge regarding palliative care and source of information. The consensus among the treating doctors and further course of treatment was documented. The futility of continuing aggressive treatment and its probable consequences was inquired from caregivers. Need for interventions, prolonging life support (mechanical ventilation, invasive lines, vasopressors, and dialysis), and resuscitation were inquired with caregivers. Nature of comfort care and level of care were asked including their will to give home-based or institution-based hospice care. Financial issues and support were inquired and their impact in initiating palliative care or foregoing life-supporting treatment was inquired.

Statistical analysis

This was a pilot study as no data are available with regard to awareness and attitude toward EOLC in primary caregivers of advanced cancer patients requiring EOLC in India. Hence, a formal sample size calculation is not feasible. We assessed 100 primary caregivers for parameters related to EOLC as per the questionnaire. The categorical data were analyzed using Fisher's exact test and Chi-square test. The intergroup correlation was done using the Chi-square and nonparametric tests. For all statistical purpose, $P < 0.05$ was considered significant.

RESULTS

In this study, 112 were approached for possible recruitment, and finally, 100 caregivers completed the study as others either did not consented or a primary caregiver could not be identified for the study purpose. The patients included were advanced

cancer patients and most of them have received some form of cancer therapy [Table 1]. The primary caregivers were male, middle age, married, graduate educated, and urban resident belonging to the middle class [Table 2]. In 27% of cases, the caregivers were the son; in 22% of cases it was the spouse; and 20% of cases it was others.

The data were tabulated for comparison of study parameters with a demographic profile of primary caregivers [Table 3].

Table 1: Demographic characteristics of the patient

Characteristics	Number (n=100)
Age (years), mean±SD	49±16.56
Gender (male:female), n	43:57
Diagnosis, n	
Head-and-neck cancer	5
Breast	15
Lung cancer	7
Gastrointestinal cancers	2
Hepatobiliary	6
Genitourinary	2
Soft-tissues tumors	2
Hematological malignancies	9
Others	52
Treatment received, n	
None	1
Chemotherapy alone	56
Radiotherapy alone	52
Surgery alone	32
Chemotherapy and radiotherapy	47
Combination of chemotherapy, radiotherapy, surgery	53
Duration of diagnosis of cancer (years)	3

SD: Standard deviation

Table 2: Demographic characteristics of the primary caregivers

Characteristics	Number (n=100)
Age (years), mean±SD	35±15
Age distribution (years)	
18- 30	23
31- 45	54
46- 60	21
>60	2
Gender (male:female), n	74:26
Marital status (single:married:divorcee:widower)	24:58:8:10
Educational level (illiterate:matriculation:higher secondary:graduate and above)	13:12:18:57
Habitat (rural:urban:semiurban)	24:48:28
Occupation (service:business:agriculture:others)	57:24:15:4
Social starta-Kuppaswamy scale (upper:middle:lower)	18:44:38
Relationship with the patient (son:daughter:wife:husband:father:mother:others)	25:17:29:15:8:5:1
Number of family members (1:2:3:4:5:>5)	6:38:33:16:6:4

SD: Standard deviation

All of the primary caregivers were aware of the disease, but only 28% of primary caregivers know the exact stage of the cancer. Furthermore, the consequences of the outcome of disease, EOLC understanding, understanding the futility for definitive care, acceptability, and understanding of palliative care lacked in most of the caregivers. However, all caregivers wanted to have comfortable EOLC along with home care facility. In this study, 70% of males and 30% females were aware of the primary cancer. The 44% of the middle age group and 35% person with education of graduation and above were aware of the extent and spread of cancer. Most of these caregivers belonged to the urban population (45%) and middle class (41%). In this study, 37% of males and 62% of females understood the term EOLC ($P = 0.034$) and 52% of the middle-aged group and mostly the graduates (39%) were aware of the term EOLC. Another contrasting result is that 41% of the rural populations were aware of the EOLC as compared with 27% urban attendants ($P = 0.044$). Nearly 43% of the middle class and 33% of the upper class were aware of the same. Furthermore, 64% of females and 36% of males understand that continuing full therapy will result in prolonging the agony of death ($P = 0.033$). Similarly, 57% of the graduates versus 39% of the illiterate people agreed with discontinuation of definitive therapy, whereas 40% of rural and only 13% of urban population agreed with the futility of therapy ($P = 0.042$). The futility of therapy was not statistically significant when compared between lower (30%) and upper class population (28%). Almost 80% of subjects (mostly middle class) wanted more information about palliative care, which should be freely available. In our study, it was the cancer survivor relatives who were the main source of information (45%), followed by Internet (30%), 18% from media, and the rest 7% from hospital staff. We observed that 63% of females and 37% of males wanted to forego intensive care unit (ICU) support (mechanical ventilation and resuscitation) ($P = 0.034$). In addition, 64% of old age group refused ICU admission. They believe that it was an unnecessary wastage of resources. Among various places of residence, 40% of rural and 13% of urban population wanted to forego ICU support ($P = 0.042$), but there was also a higher percentage (42%) of people living in semi-urban areas who wanted to avoid ICU admission. About 44% of middle class and 65% and 20% of lower and upper class people, respectively, did not want to admit their patients in the ICU. It was observed that 68% of females and 32% of males wanted to initiate palliative care. Furthermore, 72% of the old age people wanted the same. Based on the literacy level, 48% of the illiterate population as compared to 28% of the graduate wanted to adopt EOLC. Based on the socioeconomic status, 27% of the upper and 42% of the lower class people wanted to adopt EOLC ($P = 0.044$). Regarding the initiation of palliative care in terminally ill patients, 47% rural background were ready for initiation of palliative care versus 18% urban class. They were willing for a home-based model of EOLC with periodic visits by some paramedical personnel. However, most of the caregivers desired that the end stage of life should be comfortable.

Table 3: Comparison of the study parameters with demographic profile of primary caregivers

Question	Overall	Gender	Age (years)	Education	Habitat	Social class
Aware of the patient's disease (none:little bit:everything)	2:30:68	Males - 2:29:69 Females - 0:33:67	18- 30→2:34:64 31- 45→2:33:65 46- 60→1:35:64 >60→1:33:66	Illiterate - 0:52:48 Matriculation - 7:14:79 High school - 0:14:86 Graduate and above - 0:17:83	Rural - 0:53:47 Semiurban - 0:30:70 Urban - 3:30:77	Lower - 0:53:47 Middle - 0:30:70 Upper - 3:20:77
Aware of the stage of cancer (yes:no)	28:72	Males - 30:70 Females - 35:65	18- 30→33:67 31- 45→34:66 46- 60→35:65 >60→27:73	Illiterate - 27:73 Matriculation - 22:78 High school - 27:73 Graduate and above - 35:65	Rural - 27:73 Semiurban - 34:66 Urban - 43:57	Lower - 26:74 Middle - 33:67 Upper - 44:56
Do you know the consequences and outcome of the disease process? (yes:no:not sure)	37:61:2	Males - 67:31:2 Females - 48:52:0	18- 30→48:8:44 31- 45→37:21:40 46- 60→30:20:50 >60→50:10:40	Illiterate - 56:44:0 Matriculation - 71:29:0 High school - 57:43:0 Graduate and above - 66:30:4	Rural - 35:65:0 Semiurban - 65:35:0 Urban - 70:27:3	Lower - 52:48:0 Middle - 60:37:3 Upper - 80:20:0
Understand end-of-life care (yes:no)	23:77	Males - 37:63 Females - 62:38	18- 30→15:85 31- 45→10:90 46- 60→52:48 >60→27:73	Illiterate - 28:72 Matriculation - 21:79 High school - 33:67 Graduate and above - 39:61	Rural - 49:51 Semiurban - 33:67 Urban - 27:73	Lower - 47:53 Middle - 43:57 Upper - 33:66
Do you understand that continuing full definitive care will lead to no fruitful outcome of your patient? (yes:no:may be)	43:13:44	Males - 39:12:49 Females - 52:14:34	18- 30→33:18:49 31- 45→30:18:52 46- 60→50:10:40 >60→51:12:34	Illiterate - 48:8:44 Matriculation - 27:21:50 High school - 29:21:50 Graduate and above - 52:9:39	Rural - 35:17:47 Semiurban - 30:15:55 Urban - 56:10:33	Lower - 36:20:44 Middle - 43:10:47 Upper - 53:7:40
Do you wish to carry full life supporting interventions which will unnecessarily prolong the dying process? (yes:no:not sure)	47:13:40	Males - 36:14:50 Females - 62:10:28	18- 30→55:5:40 31- 45→56:14:30 46- 60→55:18:28 >60→46:20:34	Illiterate - 60:4:36 Matriculation - 36:35:29 High school - 43:0:57 Graduate and above - 48:43:9	Rural - 58:17:23 Semiurban - 30:50:20 Urban - 33: 30: 37	Lower- 52:28:20 Middle - 36:33:30 Upper - 33:33:33
Would you like to initiate EOLC for your patient if given a choice? (yes:no:not sure)	41:31:28	Males - 41:26:33 Females - 43:43:14	18- 30→50:22:28 31- 45→55:27:15 46- 60→55:30:45 >60→37:33:30	Illiterate - 52:24:24 Matriculation - 57:28:14 High school - 57:28:15 Graduate and above - 35:30:5	Rural - 58:17:23 Semiurban - 30:50:20 Urban - 33:30:37	Lower - 36:16:48 Middle - 57:13:30 Upper - 53:7:40
Would you want to seek spiritual help? (yes:no)	40:60	Males - 41:59 Females - 38:62	18- 30→38:62 31- 45→15:85 46- 60→43:57 >60→40:60	Illiterate - 44:56 Matriculation - 43:57 High school - 14:86 Graduate and above - 43:57	Rural - 41:59 Semiurban - 50:50 Urban - 33:67	Lower - 32:17 Middle - 43:57 Upper - 47:53
Would you like visit at home by medical personnel? (yes:no)	96:4	Males - 94:6 Females - 100:0	18- 30→95:5 31- 45→99:1 46- 60→99:1 >60→99:1	Illiterate - 96:4 Matriculation - 93:7 High school - 100:0 Graduate and above - 96:4	Rural - 94: 6 Semiurban - 95:5 Urban - 97:3	Lower - 96:4 Middle - 97:3 Upper - 93:7
Want end of life to be comfortable? (yes:no)	100:0	Males - 100 Females - 100	18- 30→100:0 31- 45→100:0 46- 60→100:0 >60→100:0	Illiterate - 100:0 Matriculation - 100:0 High school - 100:0 Graduate and above - 100:0	Rural - 100:0 Semiurban - 100:0 Urban - 100:0	Lower - 100:0 Middle - 100:0 Upper - 100:0
Understand definitive care will lead to futility (yes:no:may be)	45:31:24	Males - 43:27:30 Females - 49:22:29	18- 30→64:16:20 31- 45→37:30:34 46- 60→35:33:32 >60→40:10:50	Illiterate - 60:4:36 Matriculation - 35:35:30 High school - 43:0:57 Graduate and above - 48:8:44	Rural - 40:4:56 Semiurban - 43:0:57 Urban - 13:27:60	Lower - 30:40:30 Middle - 40:5:55 Upper - 28:12:60
Like to forego ICU support (yes:no)	31:69	Males - 37% Females - 63%	18- 30→67:33 31- 45→60:40 46- 60→64:36 >60→55:45	Illiterate - 39:61 Matriculation - 55:45 High school - 66:34 Graduate - 57:43	Rural - 63:37 Semiurban - 42:58 Urban - 57:33	Lower - 65:35 Middle - 44: 56 Upper - 20:80

Contd...

Table 3: Contd...

Question	Overall	Gender	Age (years)	Education	Habitat	Social class
Like to initiate palliative care (yes:no:not sure)	34:47:19	Males - 32:43:25	18- 30→20:32:48	Illiterate - 48:12:40	Rural - 47:20:33	Lower - 42:24:34
		Females - 68:12:20	31- 45→18:40:42	Matriculation - 21:43:36	Semiurban - 47:18:35	Middle - 43:18:39
			46- 60→34:30:46 >60→72:8:20	High school - 32:22:33 Graduate and above - 37:18:35	Urban - 18:30:52	Upper - 27:39:34

ICU: Intensive care unit

On further analyzing the association with different groups with the urge to initiate EOLC, we found that with patients having the longest duration since diagnosis (636 ± 119 days) were most willing to adopt EOLC ($P = 0.054$). On further analyzing the association with different groups with the urge to initiate EOLC, we found that with patients having the longest duration since diagnosis (636 ± 119 days) were most willing to adopt EOLC ($P = 0.054$) and 20% of the caregivers wanted to initiate EOLC in patients who received chemotherapy alone ($P = 0.083$). Similarly, 26% of those willing to initiate EOLC had undergone radiotherapy ($P = 0.340$) and 14% of patients who got operated had caregivers interested in EOLC ($P = 0.476$). None of these were statistically significant.

DISCUSSION

We observed there is a low level of understanding of EOLC in the caregivers of patients with advanced cancers. Middle-aged graduate female belonging to the upper middle class were aware of the palliative care. Most of the people were eager to learn more about EOLC and believed that information about the same should be available more frequently. The old- and middle-aged males, farmers, or businessman by occupation had no knowledge of palliative care and wanted to continue definitive therapy. We observed that most caregivers wanted to forego resuscitation and ventilation in the ICU for terminal patients.

Palliative care is emerging in India and its awareness is increasing. Indian mindset has always been paternalistic to fight till the end and not giving up easily on your loved ones.^[4] Probably, this has led to slow integration of palliative care in our country. Till today, we believe in the myth that EOLC hastens death and is embracing eternal sufferings.^[5,6] The advances in the scientific technology have increased the economic and social burden of the caregivers of advanced cancer patients. The development of robust palliative care programs is essential to cater to these terminal patients.

In our study, we found that the awareness remains poor across the general population. Of the two-third global cancer patients who live in developing countries, <10% are aware of palliative care.^[7] In a study done by Gopal *et al.*, only 19% of the Indian population were aware of palliative care. The overall awareness was 26% in our study, which is more than the previous study, but still, it is not encouraging. We did not find any statistically significant difference in awareness in EOLC among the upper and lower class population. We observed that higher

incidence of knowledge about palliative care did not result in enthusiastic incorporation of EOLC in day-to-day lives, especially the rich urban population had only a few people wanting to initiate palliative care. They were not willing to withhold support and resuscitation in their patients, agreeing to the fact that prolongation of life support in these patients will be futile. This probably hints at lack of practical application of palliative care among the urban caregivers. On the contrary, rural people are more willing to adopt palliative care and want to take their patients home. Moreover, these people also understood the futility of continuing definitive therapy and are more amenable to take their ailing one's home. There is also a strong correlation that with an increasing number of years since diagnosis, there was a strong predicament to initiate EOLC in these patients. This is probably because the duration of suffering has been long. There is a drain of human and economic resources, and thus, such families were more amenable to adopt EOLC.

The effect of escalating costs of continuing aggressive medical care affects both the urban and rural population alike. There is a nonuniform response toward palliative care in India, on the one hand, we need to increase the awareness of the subject among the lower middle class and rural population, while on the other hand, we need to increase its practical application among the urban learned people. Our study seconded that people still believe that adoption of palliation is synonymous with the hastening of death.^[8] The Indian scenario has many lacunae in the adoption and implementation of EOLC in the community at large. Many physicians are still not confident to imbibe EOLC practices on their patients, and hence, new laws are needed in the Indian medical system which embraces the values of terminal care.^[9]

The only source of information about palliative care was obtained from friends or relatives who have been cancer survivors.^[10] There is a lack of integrated learning programs and campaigns to educate the masses about palliative care. Kerala ranks number one and is probably the only state that has been able to implement palliative services as a community outreach program.^[11] Most of the time, the patient comes at the advanced stage of cancer, the time to initiate palliative care is a dilemma in our scenario. Ideally, palliative care services should be provided from the time of diagnosis of the terminal disease, adapting to the increasing needs of cancer patients and their families as the disease progress. Unfortunately, in our survey, we have found that even the learned urban population

is unwilling to withdraw curative therapy even after the doctors have agreed upon futility. The recognition of medical futility is very important and needs to be implemented daily in the hospital or ICU rounds.^[12] Less than 3% of the Indian cancer patients have access to better pain relief and palliative services.^[13] The availability of opioid is a constant problem for pain physicians and palliative care providers in India.^[14] In our study, 88% of the caregivers have said that elimination of pain should be the prime aim of palliative care services. The idea is to give relief of the daily sufferings from pain by constant palliation and psychosocial and spiritual support.

It is better to identify one caregiver who can be involved in the disclosure and discussion process.^[15] In a study done by Joseph *et al.*, they found that both urban and rural population believed that bad news should be broken as early as possible and there was a unifying opinion among all caregivers that it should not be held from the patient.^[8] Palliative care improved QOL in 91% of patients with terminal cancer and prolonged survival in 15% of cases. This breaks a popular myth that palliative care hastens death, and it highlights that a patient can fulfill his/her wishes of life and embrace a dignified death while the family copes up with the loss and bereavement.

The change is required among caregivers for better understanding of palliative care and may be achieved through creating awareness and involving them in decision making at the appropriate time.^[16] The increase in awareness will lead to change in attitude toward such patients. We observed from our study that despite awareness about palliative care among urban population, willingness to de-escalate treatment was not acceptable even for patient with terminal illness. The fact stated in our study is despite awareness about palliative care the urban population is not willing to de-escalate treatment shows that the awareness is not succinct and mature. Inadequate awareness gives rise to caregivers developing unrealistic hopes of getting cancer cured.^[17] Not only a good communication but also knowledge of beliefs by physicians shall improve the acceptance of EOLC.^[18]

It has been advocated that palliative care should be made an international human right for patients suffering from a terminal illness and promoting choice, autonomy, and equity of access to services for all.^[19] The cultural and social taboos remains the limiting factors to discuss about the death in the society.^[20] Moreover, they also highlighted that lack of funding and financial support from the government is also an issue. Our study highlighted that 98% of caregivers said that they feel financial burden an issue, only a mere 8.5% of people received government support.

Of significance to discuss is the preferred place to receive palliative care, most studies have recorded that most people wish to die at home.^[21] In our study, unfortunately, most caregivers wanted to opt for a hospital or institutionalized care as they were unwilling to take patients to home. This also highlights the failure of the government to set up hospice and palliative care homes at our perusal.

This study may be limited by the fact that it was done in the referral cancer center of the country, so the awareness level at the periphery may not be generalized.

CONCLUSION

We conclude that the awareness about EOLC remains poor in caregiver if patients with advanced cancer in spite of good awareness of the disease. The consequences of the outcome of disease, awareness about EOLC, understanding the futility for definitive care, and acceptability of palliative care lacked in most of the caregivers. Furthermore, patients having the longest duration since diagnosis were most willing to adopt EOLC.

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Conflicts of interest

There are no conflicts of interest.

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