

Feasibility and Acceptability of Implementing the Integrated Care Plan for the Dying in the Indian Setting: Survey of Perspectives of Indian Palliative Care Providers

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Abstract

Introduction: Capacity to provide end-of-life care in India is scored as 0.6/100, and very few people in India have access to palliative and end-of-life care. Lack of end-of-life care provision in India has led to a significant number of people receiving inappropriate medical treatment at the end of life, with no access to pain and symptom control and high treatment costs. The International Collaborative for the Best Care for the Dying Person is an initiative that offers the opportunity to apply international evidence on the key factors required to provide best care for the dying in the Indian context. The aim of this study is to ascertain the perceptions of Indian palliative care providers regarding the feasibility and acceptability of implementing the international program in the Indian setting. **Methods:** Thirty participants from 16 palliative care centers who had participated in the foundation course of the International Collaborative for Best Care for the Dying Person were purposively chosen for the study. All participants were asked to complete the survey questionnaire that had both open- and close-ended questions. **Results:** Twenty-three participants completed this survey. The majority of items in the international program were considered relevant, representative of end-of-life care and acceptable in Indian setting. However, participants felt that the concept of the multidisciplinary team (MDT) being responsible for recognizing death may not be possible in the existing Indian setting and a senior doctor may not always be available to document a MDT decision. Some participants felt that in the Indian setting, it was not always possible to communicate about the dying process and make patient aware of the same. A small number of participants felt that using leaflets for communicating end-of-life care process may not be always possible due to logistic reasons and cost. Six participants felt that giving the dying person the opportunity to discuss their wishes, feelings, faith, beliefs, and values may not be possible, representative, and not applicable in Indian setting. The majority of participants felt that using equipment such as a syringe driver for continuous infusion is relevant ($n = 16$) and representative ($n = 13$) of end-of-life care, however most thought that it could be challenging to apply in an Indian setting ($n = 17$), including concerns about lack of familiarity and knowledge and applicability in home care settings. Six participants had reservations regarding the limitation of life-sustaining treatment and felt that discussion and review of cardiopulmonary resuscitation should happen prior to patients entering their end-of-life phase. While most participants thought relevance, representation, and applicability of assessing skin integrity as important, a few participants felt this assessment challenging, especially in home setting, and recommended Braden scale to be used instead of Waterlow for assessing skin integrity. Most participants agreed on the importance of assisted hydration and nutrition; however, again a minority highlighted challenges in this area. Five participants felt that they would sometimes continue hydration under duress from a patient's family. Participants agreed unanimously on the relevance and representation of recording of physical symptoms by MDT—initial and ongoing—with a few participants indicating that frequent observations recommended in the care plan may not be feasible in home care setting. The majority also agreed on the relevance, representation ($n = 21$), and applicability ($n = 18$) of providing written information about after-death care, with a small number indicating challenges in the Indian setting, for example, very few unit currently having this information available ($n = 2$). Notifying general practitioners, primary care physicians, and other appropriate services on patients' death may not be easily applicable in the Indian setting. **Conclusions:** The survey of palliative care providers about the feasibility and acceptability of integrated care plan at end of life has shown that the international program is relevant, representative of end-of-life care, and acceptable in Indian setting. As would be expected, a number of items need

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careful consideration and appropriate modification to ensure relevance, representation, and applicability to Indian sociocultural context. The results also suggest that palliative care providers need additional training for the implementation of some of the items in the development of an India-specific document and supporting quality improvement program.

Keywords: Dying, India, integrated care plan, palliative care, survey

INTRODUCTION

According to the Global Atlas of Palliative care, palliative and end-of-life care need in the South East Asian Region (SEAR) is estimated to be around 175–275/100,000 population.^[1] The SEAR constitutes 24% of the world's palliative and end-of-life care needs. The 2015 Quality of Death Index ranking palliative care across the world has ranked India at 67th among the eighty countries studied. According to this report, poor quality of end-of-life care delivery in India is secondary to poor government-led strategy toward national-level palliative care, lack of training of health professionals in palliative care and a shortage of specialist palliative care providers, limitation of public funds, lack of availability of opioid analgesics, and poor public awareness about palliative and end-of-life care. The capacity to deliver palliative and end-of-life care is scored as 0.6/100, i.e., only 0.4% of the population in India have access to palliative and end-of-life care.^[2] Although morphine is included in the National Essential Medicines list, the current morphine and morphine-equivalent opioid utilization in India is <1 mg per capita.^[3]

A study conducted at Pune showed that 83% of people in India would prefer to die at home.^[4] However, due to a lack of palliative and end-of-life care provision, patients receive inappropriate aggressive medical interventions at the end of life, which drain the resources of patients and family.^[5] In India, 80%–85% of the population spend out of pocket for their health-related expenses and around 39 million individuals becoming poorer every year due to rising health-related costs. Most of these costs are related to aggressive medical interventions in the last few days of life.^[6] Cost of medical care and nonavailability of palliative care at end of life has forced up to 78% of patients in advanced stages of illness to leave the hospital Intensive Care Units against medical advice.^[7] Families unilaterally initiate these discharges and these discharged patients do not receive any symptom relief or care at end of life. There are no legal frameworks or policies backing the clinicians on palliative and end-of-life care. Nonexistent national palliative care policy and ambiguous legal position are the most important detriments for the provision of effective end-of-life care in India.^[8]

The Integrated Care Pathways and Care Plans are now commonly used in many areas of medicine. Their evolution stems from the concept of the Integrated Clinical Pathways, first introduced in 1985.^[9]

The Liverpool Care Pathway (LCP) is an approach developed in the UK during the 1990s between the Royal Liverpool Hospital and Marie Curie Palliative Care Institute (MCPCIL).

It was intended to provide the best possible quality of care for the dying, similar to that seen in hospices, in other settings such as hospitals, and the community. Its aim was to ensure that everyone expected to die within hours or days should receive the same high standard of care, regardless of where they were.^[10] The LCP was not a form of treatment, rather it sets out guidance on a range of different aspects of care, including comfort measures; anticipatory prescribing of medicines; discontinuation of interventions that were no longer necessary or in the patients' best interests; psychological and spiritual care; and care of the family.^[11] A range of support materials was made available including template documents; training for health-care staff; and arrangements for audit and evaluation including feedback regarding use of the LCP and its outcomes.^[12]

Initial assessments of the effects of the pathway were largely positive. Nurses saw the pathway as having a beneficial effect for patients and their families, and in another study, doctors too felt the approach to be valuable.^[13,14] A subsequent study 2 years later found that nurses and relatives thought that the approach improved the management of patients' symptoms.^[15,16] A report from the Clinical Effectiveness and Evaluation Unit of the Royal College of Physicians (UK) stated that "where the LCP was used, people are receiving high quality clinical care in the last hours and days of life."^[17] However, its inappropriate and misguided use in certain hospitals led to increasing concerns by families regarding aspects around the prescribing and the withdrawal of nutrition/hydration without adequate consent or discussion. Following increasing and unfavorable pressure from the media, an independent review was commissioned and its findings were published in 2013. The review, led by Baroness Julia Neuberger, found that when used properly, the LCP helped patients to have a comfortable and pain-free death. However, it also heard of failings when applied badly, particularly around the instances of communication, and recommended that it has to be phased out in the UK by 2014.^[18] As Barclay pointed out "the response to poor use should be right use, not non-use."^[19] He further pointed out that the application of any guideline or integrated pathway without good clinical judgment would result in poor clinical care, since guidelines were written to guide, and not to dictate.^[19]

Meanwhile, the members of MCPCIL had been working with leaders in palliative care and oncology in several countries around the world to implement and disseminate the LCP Continuous Quality Improvement Programme. The LCP was introduced in India in 2006 through the Indian Association of Palliative Care (IAPC).^[20]

With the support from an European Union grant, a program of work to optimize research for the care of cancer patients in the last few days of life was launched in 2011 (OPCARE9), incorporating colleagues from 12 countries. In 2013, the OPCARE9 group became established as “The International Collaborative for Best Care for the Dying Person.” Their vision is for a world where all people could experience a good death as an integral part of their individual life, supported by the very best personalized care.^[21]

Against this background, leading members of the International Collaborative for the Best Care for the Dying Person were invited to conduct a foundation course based on the ten key principles and core elements of care for the dying person. The foundation course was conducted by the international experts from the collaborative. Thirty participants from 16 palliative care institutes participated in this workshop. The foundation course provided training to the participants in principles for the best care for dying person, algorithms for recognizing, communicating, involving, and supporting the dying person and family, and examples of care plans and symptom guidance.

The outcome of the foundation course was that the participants agreed to devise a new care plan for use in India. Prior to developing the care plan, it was decided to conduct a survey on the feasibility and acceptability of the agreed integrated care plan for the dying in the Indian setting.

The aim of this study is to assess the feasibility and acceptability of the agreed integrated care plan in the Indian setting.

METHODS

Study design

We used a survey method to gain information from the participants about their perceptions about the integrated care plan. The survey had a set of open- and close-ended questions. Close-ended questions elicited dichotomous response. Close-ended questions were used instead of Likert scale as the care plan has multiple items and each item has to be responded with regard to relevance, representativeness, and applicability. Pilot testing showed participant fatigue with Likert scale, and analysis of multiple items and subitems was a complex process. Open-ended questions complemented the close-ended questions and provided the participants an opportunity to provide their interpretation about each item of the integrated care plan.^[22]

Study questionnaire

The study questionnaire was prepared using an example of a “Care Plan for the Dying Person” (Doc Ref: IC002) developed by the International Collaborative for Best Care for the Dying Person. The study questionnaire was created after obtaining prior permission from the authors of the care plan. The first part of the survey questionnaire had three dichotomous (yes/no) questions for each item of the care plan. The dichotomous questions were relevance, representation, and acceptability. Researchers were interested to know whether the items in

the care plan were relevant to Indian setting, represented end-of-life care practices provided in Indian settings, and acceptable to Indian palliative care providers. The second part of the survey questionnaire had open-ended questions seeking participant’s opinion, comments, and suggestions for each item of the care plan.

Participant recruitment, sampling, and sample

An homogeneous, nonprobability, nonsequential, purposive sampling approach was used in this study.^[23] A homogeneous population of palliative care providers providing hospital or hospice-based end-of-life care were purposefully chosen in a strategic manner such that all the participants chosen were senior palliative care physicians having substantial experience in the provision of end-of-life care.^[24] Probability sampling approach was not used as this study aims to know the feasibility and acceptability of a clinical service protocol. Hence, the participants participating in this study need to be experts in the area of clinical services studied. Participant recruitment criteria were created before the commencement of the study.^[25] All participants participating in the study had participated in the 3-day foundation course conducted by the International Collaborative for the Best Care for the Dying Person. Thirty participants from 16 palliative care services across India were found eligible for the study. All the eligible participants received the study protocol, study questionnaires, and instructions to complete the questionnaires through E-mail.

RESULTS

Among the 30 participants who were sent the survey questionnaire, 21 participants completed the survey questionnaire. Results of the survey were as follows:

Recognition of dying

All participants agreed that the MDT should be involved and responsible for decision-making about recognition of the dying and subsequent end-of-life care planning. Participants felt that this approach is relevant and representative of provision of end-of-life care. Two participants felt that it may not be applicable in the Indian setting as the concept of MDT is a rarity in the Indian setting. Participants were not clear about what constituted a MDT. Participants felt that the creation of an MDT is challenging in the presence of limited number of health-care providers and the concept of MDT may not be applicable in home care setting. One participant felt that the care plan document should provide clinical pointers, which would help doctors and nurses to recognize the dying process. Although all participants felt that the senior doctor in the team should document the MDT decision about recognition of the dying, six participants felt that it may not be applicable in Indian setting. Two participants felt that senior doctors may not always be available for documentation of a MDT decision. Participants felt that there is ambiguity regarding the definition of senior doctor and it may be inappropriate to nominate one doctor as the senior doctor when the patient is simultaneously receiving care from multiple clinical teams.

All participants agreed that the care plan should be discussed with patients' carers and relatives. However, one participant felt that the term "advocate" may be misunderstood in Indian context. All participants agreed that baseline symptoms should be documented on recognition of the dying process [Table 1].

Communication and information exchange regarding recognition of the dying

All participants agreed that the dying person should participate in the communication and information exchange and should be aware of the dying process. All participants felt that it is relevant and representative of end-of-life care. Three participants felt that it may not be applicable in Indian setting as Indian patients may not always be aware of the dying process. One participant felt that the dying person may not always be alert and may not be able to comprehend information. All participants agreed that relatives should participate in the communication and information exchange and should be aware of the dying process. All participants agreed that it

is important to have contact information of the next of kin. However, few participants felt that it may not be applicable in Indian setting and they may not always possess up-to-date information of the next of kin. Although all participants agree in principle that relatives should receive full explanation of end-of-life care process and facilities, three participants felt that complete explanation may not always be possible. A few participants had strong reservation against using printed communication leaflets as it may not be feasible in a hospital setting and may experience difficulty in printing leaflets in multiple languages [Table 2].

Spirituality

Six participants felt that giving the dying person the opportunity to discuss their wishes, feelings, faith, beliefs, and values may not be relevant, representative, and not applicable in Indian setting. Two participants had reservations about opportunities provided to relatives to discuss their wishes, feelings, faith, beliefs, and values. Participants felt that it may be too late

Table 1: Recognition of the dying

Item	Relevance (n=23)	Representation (n=23)	Applicability (n=23)	Summary of participant comments
MDT decision-making in recognition of the dying and subsequent planning of the end-of-life care	Yes=23	Yes=23	Yes=21 No=2	Concept of MDT is rare in Indian setting (n=1) What constitutes MDT? (n=1) How to apply MDT concept in home care setting? (n=1) How to apply MDT concept when there are limited number of staff in a team? (n=1) Document should provide pointers that would help doctors and nurses to recognize the dying process (n=1)
Senior doctor should document the MDT decision	Yes=23	Yes=23	Yes=17 No=6	Senior doctors may not always be available (n=2) Who is a senior doctor? (n=1) In a hospital setting, patients are usually seen by many senior doctors from various clinical teams (n=1)
Discussion of the care plan with the relative, carer, or advocate	Yes=23	Yes=23	Yes=23	Term advocate may be misunderstood (n=1)
Documentation of baseline symptoms at the recognition of dying process	Yes=23	Yes=23	Yes=23	All in agreement

MDT: Multidisciplinary team

Table 2: Communication and information exchange regarding recognition of the dying

Item	Relevance (n=23)	Representation (n=23)	Applicability (n=23)	Summary of participant comments
Dying person is able to take part in the communication and is aware of the dying process	Yes=23	Yes=23	Yes=20 No=3	All Indian patients may not aware of the dying process (n=3) Patients may not be alert and may not comprehend the information provided (n=1)
Relative is able to take part in the communication and is aware of the dying process	Yes=23	Yes=23	Yes=23	All in agreement
Clinical team have up-to-date contact information for the relative or carer or advocate	Yes=23	Yes=23	Yes=20 No=3	Participants felt that they always do not have contact details of the next of kin (n=4) All participants felt that they should have complete contact details of the next of kin (n=4)
Relative or carer has had a full explanation of the facilities available to them, and leaflet about the facilities is provided	Yes=23	Yes=23	Yes=23	Full explanation of the process may not always be possible (n=3) Most of the hospitals may not have leaflets (n=4) It may be difficult to print leaflets in many languages (n=4)

to discuss and may not be applicable to the current phase of disease trajectory. One participant felt that spirituality is difficult to discuss in India due to diverse religious need in India. One participant felt that spirituality has to be family centered and felt that patients' relatives may dominate spirituality discussion [Table 3].

Multidisciplinary team decision on medications

All participants agreed on anticipatory prescription writing for symptom management in end-of-life care. Seven participants felt that use of a syringe driver is not relevant, ten participants felt that it may not always be representative of end-of-life care, and 17 participants felt that it is not applicable in Indian setting. Five participants felt that it cannot be implemented in their practice setting and four participants had reservation against use in home care setting. Three participants felt that they lacked requisite knowledge regarding using syringe driver and felt easier to use intermittent subcutaneous doses [Table 4].

Multidisciplinary team decision-making on interventions

The majority of the participants agreed that the practice of routine blood investigations, monitoring vital signs, routine use of intravenous antibiotics, and oxygen therapy should be reviewed at end of life. Although the majority of participants felt that cardiopulmonary resuscitation status should be reviewed and is relevant at end of life, five participants felt that it may not be representative of the end-of-life care provision and six participants felt that it may not be applicable in Indian context. Six participants felt that discussion and review of cardiopulmonary resuscitation should happen prior to patients entering the end-of-life phase and two participants felt that resuscitation team should be called if the cardiopulmonary arrest was unanticipated. Most of the participants felt that deactivation of implantable cardioverter defibrillator is

relevant in end-of-life care, four participants felt that it was not representative of end-of-life care, and ten participants felt that it was not applicable in Indian setting. Although majority felt that assessment of skin integrity is relevant and representative of end of life, Waterlow scoring system was not a familiar tool and one participant has suggested a change to Braden's scale. A few participants felt that the assessment of skin integrity in end of life is difficult, especially in the home setting, and would normally advice the nurses to assess for skin integrity [Table 5].

Clinically assisted nutrition and hydration

The majority of participants felt that reviewing clinically assisted nutrition and hydration at end of life and discussing the same with patient and family is relevant and representative of end-of-life care. However, four participants felt that it may not be applicable in Indian setting. Three participants felt that they will continue assisted nutrition if clinically indicated. Five participants felt that they will continue hydration under duress [Tables 6 and 7].

Communication regarding plan of care

All participants felt that communication regarding a plan of care to patients and their families is relevant in end-of-life care. All participants felt that provision of leaflet informing end-of-life process and general practitioner (GP) involved in the care process is relevant in end-of-life care. However, four participants felt that these are not representative of end-of-life care and five participants felt that these may not be applicable in the Indian setting. Nine participants felt that GP is not usually involved in the care process in end of life [Table 8].

Initial and ongoing assessment

All participants felt that physical symptoms should be assessed and recorded by the MDT team. The personal hygiene needs

Table 3: Spirituality

Item	Relevance (n=23)	Representation (n=23)	Applicability (n=23)	Summary of participant comments
The dying person is given the opportunity to discuss their wishes, feelings, faith, beliefs, and values	Yes=17 No=6	Yes=17 No=6	Yes=17 No=6	Too late to discuss (n=2) Not applicable at this stage (n=3) Spirituality should be family centered (n=1)
The relatives are given the opportunity to discuss their wishes, feelings, faith, beliefs, and values	Yes=21 No=2	Yes=21 No=2	Yes=21 No=2	Difficult to achieve spirituality discussions due to diverse religious needs in India (n=1) Relatives may "dominate" the spirituality discussion (n=1)

Table 4: Multidisciplinary team decision-making on medications

Item	Relevance (n=23)	Representation (n=23)	Applicability (n=23)	Summary of participant comments
Anticipatory prescription for symptom management in end of life	Yes=23	Yes=23	Yes=23	All in agreement
Equipment is available for the patient to support a CSCI of medication where required	Yes=16 No=7	Yes=13 No=10	Yes=6 No=17	Cannot be implemented (n=5) Difficult to use in home care setting (n=4) Lack of familiarity and knowledge about syringe drivers (n=3) Easier to use 4 hourly subcutaneous doses (n=3)

CSCI: Continuous subcutaneous infusion

Table 5: Multidisciplinary team decision-making on review of interventions

Item	Relevance (n=23)	Representation (n=23)	Applicability (n=23)	Summary of participant comments
Review of blood investigations, monitoring routine vital signs, oxygen therapy, and intravenous antibiotics	Yes=22 No=1	Yes=22 No=1	Yes=22 No=1	Resuscitation status should be discussed well in advance and documented (n=6) Resuscitation status very rarely discussed with patients (n=1)
Review of cardiopulmonary resuscitation status	Yes=21 No=2	Yes=18 No=5	Yes=17 No=6	Would call for resuscitation team if death is unexpected (n=2)
Deactivation of ICD	Yes=19 No=4	Yes=19 No=4	Yes=13 No=10	ICD not relevant to most clinical settings (n=1)
Assessment of dying person's skin integrity using Waterlow scoring method	Yes=21 No=2	Yes=20 No=3	Yes=18 No=5	Assessment of skin integrity irrelevant in this setting (n=2) Would advise nurses to assess for skin integrity (n=4) Difficult to assess skin integrity (n=4) Difficult to assess skin integrity at home (n=3) Waterlow scoring not understood by the majority (n=1) Braden's score is more useful (n=2)

ICD: Implantable cardioverter defibrillator

Table 6: Assessment of person's need for food by the multidisciplinary team and review of clinically assisted nutrition

Item	Relevance (n=23)	Representation (n=23)	Applicability (n=23)	Summary of participant comments
The need for clinically assisted (artificial) nutrition is reviewed by the MDT	Yes=21 No=2	Yes=21 No=2	Yes=19 No=4	Important to review need for clinically assisted nutrition. However, difficult to discuss with the relatives (n=1)
This review is discussed with the person where possible and deemed appropriate and with the relative or carer/advocate	Yes=21 No=2	Yes=21 No=2	Yes=19 No=4	Would like to continue if clinically justified (n=3)

MDT: Multidisciplinary team

Table 7: Assessment of person's need for fluids by the multidisciplinary team and review of clinically assisted hydration

Item	Relevance (n=23)	Representation (n=23)	Applicability (n=23)	Summary of participant comments
The need for clinically assisted (artificial) hydration is reviewed by the MDT	Yes=21 No=2	Yes=21 No=2	Yes=19 No=4	Will continue hydration under family duress (n=5) Will provide hydration only if the dying person is dehydrated (n=1)
This review is discussed with the person where possible and deemed appropriate and with the relative or carer/advocate	Yes=21 No=2	Yes=21 No=2	Yes=19 No=4	

MDT: Multidisciplinary team

Table 8: Communication regarding the current plan of care

Item	Relevance (n=23)	Representation (n=23)	Applicability (n=23)	Summary of participant comments
A full explanation of the current plan of care is given to the person	Yes=23	Yes=19 No=4	Yes=18 No=5	Care plan is seldom discussed with the patient (n=1) Most palliative care units do not have a leaflet (n=1)
A full explanation of the current plan of care is given to the relative or carer/advocate	Yes=23	Yes=19 No=4	Yes=18 No=5	Not always possible to provide a full explanation to relatives (n=1)
A leaflet is given to the relative or carer/advocate to explain what changes may occur before death	Yes=23	Yes=19 No=4	Yes=18 No=5	GP/primary health-care team is usually not informed (n=9) Majority of patients may not have a GP and GPs may not be interested to know (n=1)
Primary health-care team/GP is aware that the patient is thought to be dying	Yes=23	Yes=19 No=4	Yes=18 No=5	

GP: General practitioner

psychological well-being and the supportive care environment needs to be routinely assessed.

The majority of the participants felt that these are representative and applicable in the Indian setting. Six participants felt that

4 hourly observation may not be appropriate in the home setting and three participants felt that 12 hourly observation is more appropriate or can be assessed on phone. Five participants felt that it is difficult to assess skin integrity at end of life and four participants have recommended substitution of the Waterlow scale with a familiar scoring system. Four participants felt that it is difficult to assess psychological needs of the patient and two participants felt that assessing psychological needs at home is very difficult [Table 9].

Care after death

All participants agreed that verification of death should be done by health-care professional and is relevant and representative of after-death care. Two participants felt that it may not always be applicable in Indian setting. Three participants felt that verification of death by health-care professionals at home and rural setting may be difficult. Majority of participants agreed that providing verbal and written information is relevant and representative of after-death care. However, five participants felt that it may not be applicable in Indian setting as very few palliative care units provide written information to the families regarding after-death processes and care. Seven participants felt that notifying GPs or the primary health-care team is not relevant and representative of end-of-life care and

12 participants felt that this may not be applicable in Indian setting as notifying GPs on death is not a routine practice and they may not be interested to know this information. Nine participants felt that informing appropriate organizations is not relevant or representative of after-death care and 17 participants felt that it is not applicable in Indian setting. Six participants felt that the term “coroner” should be replaced by a term appropriate to the sociocultural context [Table 10].

DISCUSSION

The multinational evidence shows that ten key elements were necessary to achieve the vision of best care for the dying and these elements were felt to be applicable irrespective of the place of care and transcended national and cultural boundaries.^[26-28] The integrated care plan for the dying is found on the following ten elements.

Ten key elements necessary to achieve the best care of the dying

- Recognition that the patient is in the last hours or days of life should be made by the MDT and documented by the senior doctor responsible for the patient’s care
- Communication of the recognition of dying should be shared with the patient where possible and deemed

Table 9: Initial and ongoing assessment

Item	Relevance (n=23)	Representation (n=23)	Applicability (n=23)	Summary of participant comments
Recording of physical symptoms by MDT - initial and ongoing	Yes=23	Yes=23	Yes=22 No=1	Four hourly observations too frequent in home setting (n=6) Twelve hourly observation more appropriate at home (n=3)
The person’s personal hygiene needs are met	Yes=23	Yes=22 No=1	Yes=22 No=1	Telephonic assessment of home care patients (n=3) Two hourly assessment of symptoms (n=1)
The person receives his/her care in a physical environment adjusted to support his/her individual needs	Yes=23	Yes=23	Yes=20 No=3	Skin integrity is difficult to assess (n=5) Waterlow scoring to be substituted with a familiar scoring system (n=4)
The person’s psychological well-being is maintained	Yes=23	Yes=23	Yes=20 No=3	Psychological needs difficult to assess (n=4) Psychological needs are difficult to assess at home (n=2)
The well-being of the relative or carer attending the dying person is maintained	Yes=23	Yes=23	Yes=21 No=2	

MDT: Multidisciplinary team

Table 10: Care after death

Item	Relevance (n=23)	Representation (n=23)	Applicability (n=23)	Summary of participant comments
Verification of death done by a health-care professional	Yes=23	Yes=23	Yes=21 No=2	Replace or remove the term coroner (n=6) Verification of death by health professional difficult in rural and home care setting (n=3)
The relatives or carers can express an understanding of what they will need to do next and are given relevant written information	Yes=21 No=2	Yes=21 No=2	Yes=18 No=5	Should include a question to know was the death peaceful from relative’s perspective (n=2)
The medical team, primary health-care team/GP who supports the patient in his/her usual place of residence is notified of the person’s death	Yes=16 No=7	Yes=16 No=7	Yes=11 No=12	Very few units have a written information for the relatives regarding after-death processes and care (n=2)
The person’s death is communicated to appropriate services across the organization	Yes=14 No=9	Yes=14 No=9	Yes=6 No=17	Notifying death to GP/primary care team not done as not relevant (n=1) GP/primary care team not interested to know this information (n=1)

GP: General practitioner

- appropriate and with the relative or carer or advocate
- The patient and relative/carer/advocate should have the opportunity to discuss their wishes, feelings, faith, beliefs, or values
- Anticipatory prescribing for symptoms of pain, excessive respiratory secretions, agitation, nausea and vomiting, and dyspnea should be in place
- All clinical interventions are reviewed in the best interest of the individual patient
- There should be a review of hydration needs including the commencement, continuation, or cessation of clinically assisted (artificial) hydration
- There should be a review of nutritional needs including the continuation or cessation of clinically assisted (artificial) nutrition
- There should be a full discussion of the plan of care with the patient where possible and deemed appropriate and with the relative or carer
- There should be regular assessments of the patient at least for every 4 h
- Care of the patient and relative or carer or advocate immediately after death is dignified and respectful.

In our survey, although all participants agreed on MDT decision-making for recognition of death and planning of end-of-life care, the concept of MDT was not clear to many participants.^[29] Rather than formalizing it as MDT, it may be useful to modify the term as palliative care team. Participants felt that it may not always be practical to have a senior doctor present all the time and this term could have ambiguous meaning in certain clinical situations. The term senior doctor probably needs to be replaced by primary physician of the patient or the physician designated for the care of the patient by the primary physician. The term advocate in India is easily misunderstood for a lawyer or for a person dealing with the legal system. This term probably needs to be replaced by patient representative.^[30]

All participants agreed that the dying patients and their families should be communicated and aware of the dying process. As India is socioculturally different in comparison to Western societies, concerns of some of the participants about dying person aware of the dying process may not always be possible. Indian study about patients' preference of knowing showed that patients were keen to know about their illness, treatment options, and chances of cure. However, families and doctors are reluctant to disclose in the belief that the patient does not want to know and telling him/her would lead to fear and depression.^[31] Although this study did not examine the communication in the dying process, the families' views on it may not be much different. A large study is currently underway to examine this phenomenon. Hence, it may be apt to modify the item of the care plan as the dying person is able to participate in the communication and aware of the dying process with concurrence of family. Most of the hospitals and clinical services have contact details of the next of kin and it should be made mandatory. Having leaflets about end-of-life

care process can be made optional due to logistic and cost concerns.

It was an interesting observation to see that almost one-third of the participants were not open to provide dying person an opportunity to discuss their wishes, feelings, faith, beliefs, and values. This might be due to lack of training in spiritual care and ethical challenges and barriers encountered by the Indian health-care providers in providing the spiritual care.^[32] Rather than the dying person being deprived of the opportunity of receiving spiritual care, it might be useful for the health-care providers to receive additional training in spiritual care alongside end-of-life care training. A qualitative study has shown that Western model of spiritual care may not be directly applicable in Indian setting and spiritual care provided for Indian patients has to be relevant to the sociocultural context.^[33]

There is an overwhelming view among the palliative care providers that using equipment such as a syringe driver for continuous infusion may not always be relevant and representative of end-of-life care. Majority of them felt that it is not applicable in Indian setting. A study that reviewed the current practices on syringe driver use has found that health-care providers without adequate knowledge about device use, drug combination, drug dilution and titration, and management of site reactions may have difficulties in using drug delivery systems.^[34] Rather than mandating it in the care plan, it may be useful to make it optional and include this component as a part of end-of-life care training.

In India, at present, there is a lack of legal clarity on cardiopulmonary resuscitation and it may hinder the health-care providers from limiting life-sustaining treatment at end of life. Position paper^[35] and guidelines^[36] on end-of-life care and information on legal provisions available for limiting life-sustaining treatment in India^[37] may empower the health-care providers in providing appropriate end-of-life care. This should be included as a part of the end-of-life care training. Implanted cardioverter defibrillator (ICD) is a rarity in India. However, it will be useful to provide training to health-care providers about steps involved in deactivation of the ICD as not turning it off may lead to painful electrical shocks at end of life.^[38] Braden scale is the common scale used in India to assess skin integrity and probably it should be used instead of Waterlow scale.^[39]

Health-care providers find limiting clinically assisted nutrition and hydration in the Indian setting ethically challenging. A systematic review of literature has shown that cultural norms and ethical principles of a family influence attitudes toward clinically assisted nutrition and hydration as it has symbolic meaning representing care, hope, and trust.^[40] Albeit there are definite advantages of limiting clinically assisted hydration and nutrition, it should be done after adequate communication and concurrence of the family.

Few palliative care providers felt that it may not be possible to provide full explanation of the care process to the dying person as the patient may be obtunded, have altered conscious state, or

family may not consent for the same. Hence, this item can be made optional. It may not always be possible to have a leaflet explaining the end-of-life care process for logistic reasons such as need for printing in many languages and additional costs. Hence, this item also could be made optional. An extremely small number of patients in India have GPs and GPs are not generally involved throughout the care process. Hence, this item can be made optional.

Participants felt that frequent observations at end of life may not be possible, especially at home care setting. Hence, 4 hourly observations used for hospitalized patients have to be modified for home care patients. Participants also felt that assessing psychological needs at end of life is difficult. Psychological support at end of life helps in managing distress and enhancing coping responses.^[41] Hence, this should be a part of end-of-life care training.

Although a few participants have felt that verification of death by health care-professionals may not always be feasible in rural and home care settings, certification of death by a health-care professional is an absolute requirement by law.^[42] Hence, it is important to continue this item in the care plan. Notifying GPs may not always be relevant as they are not usually involved in the hospital care process. This may be due to a large division between specialists and generalists in Indian health-care setting and usually specialists provide care to hospitalized patients. Families usually provide after-death care and funeral homes are seldom involved. Hence, notifying GPs and other organizations could be optional items in the integrated care plan.

CONCLUSIONS

Survey of palliative care providers about feasibility and acceptability of integrated care plan at end of life has shown that:

- Majority of items in the integrated care plan is relevant, representative of end-of-life care, and acceptable in Indian setting
- Use of syringe drivers for continuous subcutaneous infusion has limited applicability in India and this requirement can be met by regular intermittent and as needed subcutaneous injections of the same combination of medicines through a subcutaneous needle and cannula kept in place
- Few items need to be modified in relevance to Indian sociocultural context
- Palliative care providers need additional training for implementation of few items of the integrated care plan
- Development and implementation of the care plan needs to be supported by a robust education, quality improvement, and research program to ensure evidence-based improvement in care for dying patients in India.

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