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## Stakeholder engagement as a strategy to enhance palliative care involvement in intensive care units: A theory of change approach

Seema Rajesh Rao, MSc, MBBS<sup>a</sup>, Naveen Salins, PhD, MD, FRCP<sup>b</sup>, Bader Nael Remawi, MSc, BA<sup>c</sup>, Shwethapriya Rao, MD, MBBS<sup>d</sup>, Vishal Shanbaug, MD, MRCP<sup>d</sup>, N.R. Arjun, MD, MBBS<sup>d</sup>, Nitin Bhat, MD, MBBS<sup>e</sup>, Rajesh Shetty, FRCP, MBBS<sup>f</sup>, Sunil Karanth, MD, MBBS<sup>g</sup>, Vivek Gupta, DNB, MNAMS, MBBS<sup>h</sup>, Nikahat Jahan, MD, DNB<sup>i</sup>, Rangraj Setlur, MD, DNB, MRCPI<sup>j</sup>, Srinagesh Simha, MS, MSc, FRCP<sup>a</sup>, Catherine Walshe, PhD, MSc, BNurs(Hons), RGN<sup>k</sup>, Nancy Preston, PhD, BSc (Hons), RGN<sup>k,\*</sup>

<sup>a</sup> Karunashraya Institute for Palliative Care Education and Research, Bangalore Hospice Trust – Karunashraya, Bangalore PIN:560037, India

<sup>b</sup> Department of Palliative Medicine and Supportive Care, Kasturba Medical College Manipal, Manipal Academy of Higher Education, Tiger Circle Road, Madhav Nagar, Manipal, Udupi District, Karnataka State PIN: 576104, India

<sup>c</sup> Lancaster Medical School, Faculty of Health and Medicine, Lancaster University, UK

<sup>d</sup> Department of Critical Care, Kasturba Medical College Manipal, Manipal Academy of Higher Education, Tiger Circle Road, Madhav Nagar, Manipal, Udupi District, Karnataka State PIN: 576104, India

<sup>e</sup> Department of General Medicine, Kasturba Medical College Manipal, Manipal Academy of Higher Education, Tiger Circle Road, Madhav Nagar, Manipal, Udupi District, Karnataka State PIN: 576104, India

<sup>f</sup> Clinical Services and Lead Critical Care, Manipal Hospital Whitefield, Bangalore, Karnataka State PIN: 560066, India

<sup>g</sup> Department of Critical Care Medicine, Manipal Hospital, Old Airport Road, Bangalore, Karnataka State PIN: 560017, India

<sup>h</sup> Department of Cardiac Anaesthesia and Intensive Care, Hero DMC Heart Institute, Ludhiana, Punjab PIN:141001, India

<sup>i</sup> Department of Anaesthesiology and Critical Care, Armed Forces Medical College, Pune, Maharashtra PIN:411040, India

<sup>j</sup> Base Hospital, Barrackpore, West Bengal PIN:700120, India

<sup>k</sup> International Observatory on End of Life Care, Division of Health Research, Lancaster University, LA1 4AT, UK

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## ABSTRACT

**Background:** Adult patients admitted to intensive care units in the terminal phase experience high symptom burden, increased costs, and diminished quality of dying. There is limited literature on palliative care engagement in ICU, especially in lower-middle-income countries. This study explores a strategy to enhance palliative care engagement in ICU through a stakeholder participatory approach.

**Methods:** Theory of Change approach was used to develop a hypothetical causal pathway for palliative care integration into ICUs in India. Four facilitated workshops and fifteen research team meetings were conducted virtually over three months. Thirteen stakeholders were purposively chosen, and three facilitators conducted the workshops. Data included workshop discussion transcripts, online chat box comments, and team meeting minutes. These were collected, analysed and represented as theory of change map.

**Results:** The desired impact of palliative care integration was good death. Potential long-term outcomes identified were fewer deaths in ICUs, discharge against medical advice, and inappropriate admissions; increased referrals to palliative care; and improved patient and family satisfaction. Twelve preconditions were identified, and eleven key interventions were developed. Five overarching assumptions related to contextual factors influencing the outcomes of interventions.

\* Corresponding author.

**E-mail addresses:** [seema.rao@karunashraya.org](mailto:seema.rao@karunashraya.org) (S.R. Rao), [naveen.salins@manipal.edu](mailto:naveen.salins@manipal.edu) (N. Salins), [b.remawi@lancaster.ac.uk](mailto:b.remawi@lancaster.ac.uk) (B.N. Remawi), [shwethapriya.rao@manipal.edu](mailto:shwethapriya.rao@manipal.edu) (S. Rao), [vishal.shanbhag@manipal.edu](mailto:vishal.shanbhag@manipal.edu) (V. Shanbaug), [arjun.nr@manipal.edu](mailto:arjun.nr@manipal.edu) (N.R. Arjun), [nitin.bhat@manipal.edu](mailto:nitin.bhat@manipal.edu) (N. Bhat), [rajeshshetty@manipalhospitals.com](mailto:rajeshshetty@manipalhospitals.com) (R. Shetty), [sunil.karanth@manipalhospitals.com](mailto:sunil.karanth@manipalhospitals.com) (S. Karanth), [nagesh.simha@karunashraya.org](mailto:nagesh.simha@karunashraya.org) (S. Simha), [c.walshe@lancaster.ac.uk](mailto:c.walshe@lancaster.ac.uk) (C. Walshe), [n.j.preston@lancaster.ac.uk](mailto:n.j.preston@lancaster.ac.uk) (N. Preston).

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*Conclusion:* Theory of change framework facilitated the identification of proposed mechanisms and interventions underpinning palliative care integration in ICUs.

## 1. Introduction

Death occurs frequently in intensive care units. It is estimated that about around 10–36% of adult patients admitted into intensive care units (ICU) die [1]. However, many of those who die continue to receive complex, costly, uncomfortable interventions even when these are not of benefit, as withdrawing treatment is known to be challenging to achieve [2]. Continuing these interventions can prolong the dying process and create more burden for the patient and their families [1], compromising their quality of life and prolonging suffering [3,4]. Intensive care interventions are also financially costly, with much of the burden borne by patients and families in many healthcare systems. This results in higher out-of-pocket health spending, with catastrophic consequences for individuals and families [5]. In India, approximately 58.7% of the national healthcare expenditure is out of pocket [5], and 63 million Indians, almost 7% of the population, become poorer every year due to rising health-related expenses. Most of this health-related spending occurs during the last days of their lives [6]. These high personal costs can lead to frequent discharges from the ICU, cited as discharge against medical advice or leave against medical advice (DAMA/LAMA), due to a lack of funds to sustain ICU treatment [7–11].

A recent pan-Indian audit (95% of respondents from private ICUs) found that the overall mortality in Indian ICUs was 23.4%, with 68% of those in ICU having multi-morbidity [12]. The median ICU stay for non-survivors was nine days, and all received aggressive life-sustaining interventions, reflecting higher costs of treatment [13]. Pain was assessed in less than half the patients, while delirium and sedation in less than 20%. Around 7.6% of patients were unplanned terminal discharges, which indicated a lack of awareness about and integration of palliative care in these ICUs [12]. Foregoing life-sustaining treatment was either not practiced or not documented by physicians [13]. Despite the availability of appropriate guidelines for end-of-life and palliative care being available, the legal conundrum associated with withholding and withdrawing life-sustaining interventions, and the sociocultural, religious and economic barriers contributed to the patchy implementation of end-of-life care in Indian ICUs [13].

Introducing or improving palliative care in ICUs may have a positive effect on care outcomes, experiences and costs [2]. Although cure and survival are prioritized in the ICU settings, the scope of care is gradually expanding to include quality of life and death [14]. However, in ICUs, unmet palliative care needs are seldom addressed [15], especially in low- and middle-income countries [2,16]. These disparities are primarily due to lack of awareness and policy, insufficient providers and inadequate administrative support and planning [14]. In addition, patient preferences and attitudes of individual healthcare providers along with institutional and organizational factors also hinder palliative care provision in intensive care settings [17]. However, the integration of palliative care in the ICU is associated with cost reduction during terminal hospitalizations [18] and alleviating poverty linked to health expenditure [19]. It also enables good symptom control, reduced suffering at the end of life, and improved family satisfaction [20].

Despite the proven benefits of palliative care, successful engagement of palliative care in ICUs is impeded by clinical, organizational, professional, and system barriers. Health empowerment is a dynamic process that focuses on the purposeful participation of stakeholders involved in changing themselves and their environment by identifying inherent resources and mechanisms facilitating the change [21]. However, the mechanisms underpinning empowerment and change are seldom recognized [22]. Enhancing palliative care in the ICU requires a complex intervention package with multiple, discrete, and interacting

components [23]. The active engagement and participation of stakeholders (e.g., ICU and palliative care physicians) in developing a contextually appropriate plan are essential for its feasibility and acceptability [24]. In this study, we developed a strategy to enhance ICU palliative care engagement in an Indian context through a stakeholder participatory approach using the theory of change.

## 2. Methods

### 2.1. Design

Theory of Change uses a backward mapping approach where the intervention's desired impact or goal is determined first, followed by long-term outcomes, and the preconditions (short-term and intermediate outcomes) required to achieve it. During the stakeholder engagement, a Theory of Change approach was used to develop a hypothetical causal pathway to enhance palliative care involvement in Indian ICUs [25]. Theory of Change explores how and why the desired change is expected to happen and provides a framework to identify indicators, interventions and outcomes in the hypothetical causal pathway of impact [26,27]. The interventions and contextual conditions leading to preconditions were also explicated [25]. The common terminologies used in the Theory of Change map are presented in Table 1.

Three palliative care researchers NP, CW, BR from the UK familiar with the theory of change framework facilitated the workshops and conducted small group team meetings. Intensive care and palliative care physicians were the stakeholders. The knowledge on assumptions, long-term outcomes, preconditions, potential interventions and their probable impact was co-created through stakeholder engagement [25]. A facilitated workshop model was used, where the stakeholders and facilitators worked together to create content on a predefined deliverable [28]. Nominal group technique was used to generate ideas, prioritize the preferred options, and develop consensus at each step of the Theory of Change process. Nominal group techniques include stages introductions, silent generation of ideas, listing of ideas, discussion of ideas, ranking and voting on top ideas, discussion of voting and conclusions [29]. Each workshop had a predefined deliverable that addressed parts of the theory of change causal pathway [30].

**Table 1**  
Common Terminologies used in Theory of Change [25].

Terminology	Definition
Impact (Goal)	This is the ultimate outcome or the real-world change that the program is trying to achieve
Long-term outcome	The final outcome that the program is able to achieve on its own
Preconditions	These are intermediate outcomes, precursors, or requirements that needs to be fulfilled in order to achieve the desired final outcome
Interventions	They represent the 'action plan' that the program must undertake to bring about the preconditions (outcomes). They form the different components of the complex interventions.
Indicators	These are outcome measures that are determined and documented for each outcome. They help evaluate whether the program is making progress or achieving the intended outcome.
Ceiling of Accountability	Level at which you cease using indicators to measure the achievement of the outcomes. The program stops accepting responsibility for achieving the outcomes. This is drawn between the impact and long-term outcomes
Assumptions	These are external conditions beyond the control of the program that must exist for the outcomes to be achieved

## 2.2. Setting/population/participants

Participants were stakeholders from India who worked at the clinical intersection of intensive care and palliative care and represented anaesthesia and critical care, internal medicine and critical care, emergency medicine or palliative care. They represented public or private healthcare systems. This study was conducted during the second wave of the COVID-19 pandemic in India when the healthcare system was struggling to cope with the spiralling number of cases, rising death rates, and lack of resources. This meant that we chose to use convenience sampling to recruit those stakeholders who were accessible, available, and willing to participate in the study through snowball sampling from personal acquaintances.

## 2.3. Data collection

Four facilitated workshops were conducted over two months (April–June 2021) through a virtual video conferencing platform. Each workshop was approximately two hours. The workshops were interspersed with fifteen team meetings between facilitators and a smaller group of key stakeholders to discuss the content developed from the facilitated workshops and how it relates to the predefined deliverable and the overall causal pathway.

## 2.4. Data analysis

Content was generated through the workshop recordings, workshop minutes, and reports maintained by the facilitators. All authors had given verbal consent for the recordings. Furthermore, chat box posts, and post-workshop debrief comments were also used as data for analysis. During the team meetings, the content was refined, grouped, and represented on a whiteboard for concept mapping. The concepts generated during workshops and team meetings were congregated into variables of the causal pathway. The relationship between concepts and variables were represented as a theory of change map [17].

Each facilitated workshop focused on one predefined deliverable, which formed a part of the causal pathway of the theory of change framework. A summary of all four facilitated workshops are provided below in Table 2.

## 2.5. Workshop 1: rapport, introductions, and deciding on the impact

The facilitators and participants introduced themselves, and as a relatively small group of stakeholders, this enabled rapport building. The participants were informed of the purpose and aim of the workshops. Initially, the stakeholders were familiarised with the theory of change framework. It included an explanation of the theoretical concepts and how these are represented in a theory of change map. An ongoing PhD research project on palliative care intervention in heart failure was used to demonstrate the development of a theory of change map [31]. It was followed by a brief presentation on the concept of integrating palliative care in the ICUs. The presentation had the following broad themes A. What is palliative care? B. Why palliative care in the ICU? C. What is the role of palliative care in the ICU? D. Who will benefit from palliative care in the ICU? E. What are the benefits and barriers of palliative care in the ICU? and F. How is palliative care provided in the ICU?

After the presentation, facilitators asked the stakeholders an open-ended question as to what the impact or the real-world change that the interventions aimed at enhancing palliative care engagement in the ICU might achieve. Stakeholders were given a few minutes to consider and write down individual responses independently. Then, they were asked to present their responses to the whole group one at a time. Finally, each stakeholder was asked to prioritize and rank their responses in order of importance. All stakeholders concurred that “better end-of-life care and good death” was the most important outcome of the

**Table 2**  
Summary of the Theory of Change Workshops.

Workshop	Central Themes	Structure	Outcome
Workshop 1	Deliberate on the potential desired impact of integration of palliative care in the ICU	Rapport Building Explanation of the Theory of Change, the process and the ground rules Introduction of the concept of palliative care integration in the ICU Identification of six potential outcomes of the integration of palliative care in the ICU through nominal group technique Poll to rank the six potential outcomes in order of importance	Agreement among stakeholders of the hypothesized long-term impact of the project as better end of life care and good death Long-term outcomes, preconditions, assumptions and interventions were also explicated in the first workshop
	Identify the long-term outcomes and preconditions	Introduction of the guidelines for palliative care integration into the ICU Identification of key long-term outcomes and preconditions required to achieve the desired impact through backward mapping	Five potential long-term outcomes and 12 preconditions delineated Consensus regarding the chronological order of preconditions discussed
		Presentation by two external experts exploring the overarching assumptions	
	Workshop 3	<ul style="list-style-type: none"> <li>Identify the possible interventions for achieving the desired impact</li> <li>Identify assumptions that might influence the outcomes of interventions</li> </ul>	Possible interventions explored The contextual factors influencing the outcomes of interventions identified Presentation and discussion of the first draft of Theory of Change map
Workshop 4	Future planning	Recap of the previous workshops and snapshots of the participating institutions presented Review and refinement of the Theory of Change map	Presentation of the final ToC map

ICU-PC engagement. Although the purpose of the first workshop was to deliberate on the impact of palliative care engagement in the ICU, the discussions expounded on several points related to long-term outcomes, preconditions, interventions and assumptions. The facilitators recorded these ideas separately and discussed them in the subsequent workshops.

## 2.6. Workshop 2: long-term outcomes and preconditions

The second workshop focused on developing a shared understanding of stakeholders' views on long-term outcomes of palliative care engagement in the ICU setting. A palliative care stakeholder presented on how to develop palliative care integration in intensive care. The presentation included the following: A. Findings of the systematic review on what constitutes a good death [32] B. National Institute of Health Care Excellence (NICE) end-of-life care standards [33] C. Strategies for end-of-life capacity building in India by focusing on what is already there and what needs to be done.

After the presentation, the facilitators initiated the discussion by presenting the views expressed by the stakeholders in the earlier workshop concerning long-term outcomes. It led to identifying the key long-term outcomes that might cause the impact identified in the first workshop. Furthermore, stakeholders discussed the set of preconditions necessary to achieve long-term outcomes.

## 2.7. Workshop 3: interventions and assumptions

The third workshop focused on knowing stakeholders' views on what interventions are possible and how contextual factors might influence the outcomes of the interventions. To provide a contextual framework for planning interventions, two external experts gave a presentation on the legal aspects of limiting life-sustaining treatment and how to develop an end-of-life care policy in a tertiary hospital in India. The broad themes covered in both presentations were A. Why should we talk about the limitation of life-sustaining treatment? B. What is the limitation of life-sustaining treatment? C. When to consider the limitation of life-sustaining treatment? D. How to operationalise the process of limitation of life-sustaining treatment? E. What are the legal facilitators and barriers for limiting life-sustaining treatment in India? and F. How to develop an institutional end-of-life care policy for India?

After the presentation, like the earlier workshops, facilitators discussed stakeholders' views on what interventions are feasible and how contextual factors might enable or constrain these interventions. Consensus and ranking were achieved as in previous workshops. The first draft of the Theory of Change map was presented to the stakeholders.

## 2.8. Workshop 4: future planning

The fourth workshop focused on reviewing the theory of change map with the stakeholders and strategies to enable enhanced engagement of palliative care in the intensive care setting. The facilitators began with presenting a recap of the previous workshops, including a snapshot of the participating institutions, what was achieved in the workshops so far, and an updated theory of change map based on the former discussions. Stakeholders gave their views on the theory of change map and concepts congregated in each part of the causal pathway. It was followed by discussing the next steps that might complement the interventions identified in the theory of change map.

## 3. Results

Thirteen stakeholders from five tertiary hospitals across India participated in four facilitated workshops. All stakeholders practised in the clinical intersection areas of intensive and palliative care, and participated in all four workshops. Eight of the stakeholders had over 10 years of experience in critical care and three stakeholders had over five

years of experience in critical care and emergency medicine respectively. Three facilitators conducting the workshop were familiar with the theory of change framework. Details of the study participants are provided in Table 3.

The Checklist for Reporting Theory of Change [34] suggests a framework for reporting Theory of Change which includes reporting on: i) impact, ii) long-term outcomes, iii) preconditions, iv) ceiling of accountability, v) interventions, and vi) assumptions, which are represented in the Theory of Change map in Fig. 1.

During the first workshop, six impacts were identified which is represented in Table 4.

After the poll, the impact with the highest ranking was better end-of-life care and a good death. When the participants were asked to define a *good death* from their perspective, their responses were, A. Patient is comfortable with process and outcomes, B. Family is around, C. Making choices, D. Considering last wishes, E. Individualised care, F. Appropriate interventions, and G. Symptom relief. During the second and third workshops, long-term outcomes, preconditions, interventions and assumptions were identified. The ceiling of accountability was the threshold at which the palliative care intervention in the ICU was no longer directly accountable for the desired impact. The ceiling of accountability in this study was situated between the impact of achieving a good death and the long-term outcomes contributing to the impact.

In the fourth workshop, the stakeholders identified the following strategies that might complement the interventions (see Fig. 1) identified in the Theory of Change map. They were

- 1) Developing an education program for healthcare professionals on palliative care in the ICU modelled on the Education in Palliative and End-of-life Care (EPEC) template. The participants decided to develop EPEC-ICU adaptation, and an outline of the program was introduced in the fourth workshop. Each module, and its objectives, were presented to the participants to discuss and comment on its appropriateness, relevance, and missing items. A total of 24 modules will form the EPEC-ICU adaptation, and permission was sought from the EPEC to develop this adaptation.
- 2) To develop a patient and family information guide and conduct public awareness programmes for patients and families on palliative care in critical illness.
- 3) To plan a weekly one-hour webinar series for healthcare professionals on palliative care in the ICU. Each webinar will have a palliative care and intensive care expert. Six webinars were planned to cover broad themes like the appropriateness of palliative care in ICU, medical futility and potentially inappropriate treatment,

**Table 3**  
Characteristics of the study participants (Stakeholders) in the Theory of Change Workshops (n = 4).

Characteristics <sup>a</sup>	Workshop 1 n = 13	Workshop 2 n = 12	Workshop 3 n = 11	Workshop 4 n = 12
Gender				
Male	10	9	8	9
Female	3	3	3	3
Primary profession				
Anaesthesia and critical care	6	6	6	6
Internal medicine and critical care	3	3	2	3
Emergency medicine	1	0	0	0
Palliative care	3	3	3	3
Employer				
Public Hospital	2	2	2	2
Private Hospital	9	8	7	8
Non-Governmental Organization	2	2	2	2

<sup>a</sup> The same participants attended all the four workshops.



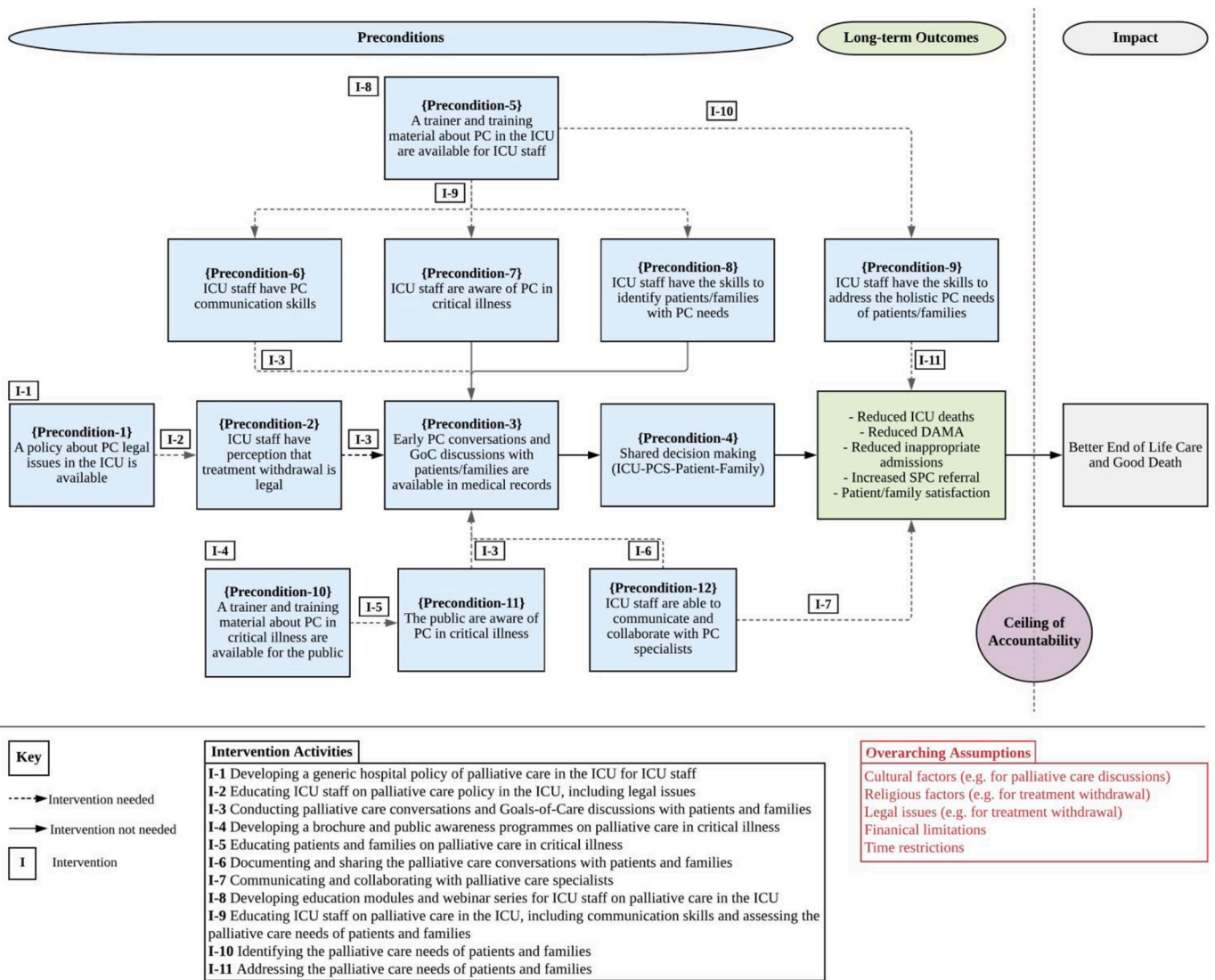


Fig. 1. Theory of Change map of PC-ICU integration.

Table 4  
The impacts of palliative care engagement in ICU.

Ranking	Impact
1	Better end-of-life care and a good death
2	Not to prolong the process of dying
3	Earlier palliative care conversations with patients and families
4	Reduced inappropriate admissions
5	Reduced ICU deaths
6	Reduced discharge against medical advice

symptom management in ICU, ethical and legal aspects of limiting life-sustaining treatment, and palliative care capacity building and sharing institutional experiences of providing palliative care in ICU. These webinars were conducted during August and September 2021. (See Supplementary material).

4) To develop a generic version of hospital end-of-life care policy with an ICU focus. The policy was presented to the participants to discuss and comment on its feasibility, relevance, and missing items.

4. Discussion

The key output from this study is the production of a robustly

generated theory of change (Fig. 1) that outlines 12 preconditions, 11 intervention activities, 6 outcomes and the anticipated impact of greater collaboration between intensive care and palliative care clinicians in ICUs. Stakeholders believed that communication, goals of care discussion and shared decision-making were the preconditions for achieving long-term outcomes. They felt that it is essential to elicit care preferences and document them. This theory of change can be used as the basis for future intervention development, and to assess the outcomes and impact of interventions. Involving palliative care clinicians in the care of those who are dying in ICU has been shown to improve the quality and outcomes of care [35]. Palliative care engagement in ICU improved patient-centred communication, goals of care discussion, documentation of patient’s wishes and advanced directives [36-40]. Furthermore, palliative care involvement meant that resuscitation preferences were documented early [37], and patients with palliative care consultations had higher documentation of do not resuscitate orders [39,41-43]. Palliative care involvement minimized terminal ICU admissions [42,44,45], length of stay in ICU [42,43,45,46], unnecessary procedures at the end of life [42,47], decreased ICU deaths and bettered symptom management [35,48,49]. It is likely then that the interventions suggested in this theory of change could enable major quality improvements. Implementing change is known to be challenging. The findings of this study indicate a perception that referral policies and education

resources for ICU providers might improve awareness of ICU providers, patients and their families and could enhance ICU palliative care engagement. Several studies have discussed the role of trigger tools as a facilitator for palliative care referral in the ICU setting [44,48,50-57]. Although these tools might enable early recognition of palliative care needs, they may not always be sensitive and accurate [56]. Moreover, the palliative care referral triggers tools used in the ICU must be comprehensive [55], and evidence-based [53], and should include frailty as an essential criterion [44]. ICU providers' lack of knowledge and understanding about the scope of palliative care might hinder integration [35,58-60]. ICU providers' prognostication skills and holistic assessment of palliative care needs were also preconditions identified in this study. Training of ICU providers might change their perceptions about end-of-life care decision-making and improve their palliative care skills [43,61]. A study showed that ICU providers working with palliative care had skills in prognostication, conflict mediation, empathetic communication and family-centred approaches [62]. Excellent inter-team communication was identified as an intervention in this study. It could be achieved by a multi-disciplinary team approach, improving familiarity through informal or formal meetings, and a collaborative shared care approach [36,49]. It might facilitate timely palliative care referral, which is a long-term outcome identified in this study.

The influence of sociocultural and legal factors was also found to be important pre-conditions in the theory of change, particularly related to perceptions about limitations in life-sustaining treatment, and discharges against medical advice. Although there is adequate protection for the healthcare providers within existing laws [63], most healthcare providers still perceive withholding and withdrawing life-sustaining treatment as illegal. The issue of discharge against medical advice is particularly contextual to India. It is a significant healthcare challenge in India, with a prevalence rate ranging over 3% [64,65]. Most of these patients are discharged from the ICUs against medical advice and are deprived of end-of-life care after discharge [65].

#### 4.1. Strengths and limitations

The participation of a small number of stakeholders, using convenience sampling, from a limited number of institutes and lack of pan-India representation could be a study limitation. Only medical clinicians were involved as stakeholders, and patient and family perspectives were not sought. This theory of change, therefore, is only derived from particular medical perspectives, which may not fully reflect the totality of the pre-requisites, interventions, outcomes and impact. However, this does reflect the typical ways that ICUs are managed in India, and so is still likely to capture the majority of requirements for the theory of change. However, it might not have been possible to accommodate more participants and collate their views during facilitated workshops [66]. Moreover, ensuring the participation of all the stakeholders in every workshop would be challenging. Indicators are measurable evidence that demonstrates the achievement of outcomes and are important components of Theory of Change [66]. In this study, no indicators or outcome measures for the preconditions and long-term outcomes had been agreed upon or proposed. This could be another limitation of the study. Conducting this study at the height of one of the waves of the COVID-19 pandemic may also have influenced findings in ways that cannot be known. However, participants drew openly from care delivered pre-pandemic and acknowledged the current context, so the likelihood that this affected the final theory of change is slight.

The study strengths were the participants' and facilitators' expertise, well-conducted workshops and meetings, systematic data collection, and schematic representations of concepts in the Theory of Change map. The participatory nature of the Theory of Change approach ensured the development of relevant and implementable interventions that could address the preconditions and long-term outcomes.

## 5. Conclusions and recommendations

This is the first study conducted in India to identify strategies to enhance palliative care engagement in Indian ICUs. A causal pathway of mechanisms underpinning enhanced engagement of palliative care in the Indian ICUs was proposed. A good death is the ultimate impact of engagement, which could be achieved by early referrals, decreasing ICU admissions and ICU deaths, and minimising discharges against medical advice. Creating educational resources, training ICU providers, developing ICU-specific end-of-life care policies, and fostering excellent inter-team communication might facilitate palliative care capacity building in Indian ICUs. There is also a possibility of conducting future research to know the effectiveness of specific interventions identified in the theory of change map. The study outcomes thus have the potential to bring about a transformational change by changing the perception of palliative care and facilitating palliative care engagement in the ICUs in low- and middle-income countries.

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### Credit authorship contribution statement

**Seema Rajesh Rao:** Methodology, Data Curation, Formal analysis, Investigation, Project administration, Writing – original draft, Writing – review & editing. **Naveen Salins:** Conceptualization, Data Curation, Methodology, Formal Analysis, Investigation, Writing – review & editing, Funding acquisition. **Bader Nael Remawi:** Methodology, Formal analysis, Investigation, Writing – review & editing. **Srinagesh Simha:** Methodology, Investigation, Writing – review & editing. **Nancy Preston:** Conceptualization, Methodology, Data Curation, Formal analysis, Investigation, Writing – review & editing, Funding acquisition. **Catherine Walshe:** Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft, Writing – review & editing, Funding acquisition. **Shwetapriya Rao:** Writing – review & editing. **Vishal Shanbaug:** Writing – review & editing. **N.R. Arjun:** Writing – review & editing. **Nitin Bhat:** Writing – review & editing. **Rajesh Shetty:** Writing – review & editing. **Sunil Karanth:** Writing – review & editing. **Vivek Gupta:** Writing – review & editing. **Nikahat Jahan:** Writing – review & editing. **Rangraj Setlur:** Writing – review & editing.

### Declaration of Competing Interest

The Authors declare that there is no conflict of interest.

### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jcrc.2022.154244>.

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