賽馬會安寧頌
JCECC
Jockey Club End-of-Life Community Care Project

INITIATED AND FUNDED BY:
The Hong Kong Jockey Club Charities Trust

PARTNER INSTITUTION:
Faculty of Social Sciences
The University of Hong Kong
香港大學社會科學學院
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GUIDEBOOK ON

INTEGRATED COMMUNITY END-OF-LIFE CARE SUPPORT TEAM (ICEST)

Volume 1

Theoretical Background, Holistic Assessment & Care Planning

First edition

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PREFACE

There were over 40 000 deaths in Hong Kong each year, with the majority from chronic illnesses. The quality of life in the final days of the patients, in particular for Chinese, has an intense impact on the families. The JCECC project, which was launched in 2016, dedicates to improve the quality of life of patients facing terminal illness.

Though the hospital is perceived as the place of care for patients in their final days, the reality differs. According to the data provided by the Hospital Authority in 2015, elderly patients with chronic illness spent about 39 days of their final six months of life in hospitals, implying more than 78% of the time were in the community. In our population survey with the general public in 2021, around 28% of respondents indicated their home as the preferred place of care when facing impending death. Therefore, end–of–life care is not only provided by the hospitals only. Instead, it can be by the community, for the community and in the community.

As suggested by World Health Organization[1], improved access to palliative care was an international mission, emphasizing expansion to community/home–based care. This requires collaborations between health care sectors, social service sectors, and community carers to coordinate and holistic care that meets the multi–dimensional needs of patients and families and honouring their wishes.

With the concerted efforts of our Project partners, a standardized and multi–disciplinary service model "Integrated Community End–of–Life Care Support Team (ICEST)" model was developed and tested. Evidence shows that the ICEST model is effective in promoting the quality of life of patients and their family carers who used the services provided by ICEST. At the same time, it reduced unnecessary hospitalization of patients and had a significant impact on society as a whole.

This guidebook aims to unveil the details of ICEST. It is divided into two volumes, with Volume One focusing on the theoretical background and the overview of the ICEST model. In addition, the practices in engagement, assessment and care planning will be outlined. This Volume will be accessible to all professionals or those professionals in training. Volume Two concentrates on the intervention. Stratified intervention directions, based on extensive literature reviews, discussions in consultative meetings with the ICEST of JCECC Project, and data collected from the evaluation of the JCECC projects, are the core features of the Volume. As the content is practice–related, a parallel ICEST training course will be offered for practicing the application of assessment, planning and practice. Volume Two will only be distributed to those who have completed this parallel ICEST training course. The English guidebook is translated into Chinese as well, hoping to meet the different learners' preferences.

Moreover, a Chinese version of another practice guidebook is published for supporting care workers. Hopefully, this guidebook and the practice guidebook can support the team members' collaboration. Ultimately, the team can provide holistic and consistent care for patients and families.

1 World Health Organization. (2016). *Planning and implementing palliative care services: a guide for programme managers.* World Health Organization. Retrieved from https://apps.who.int/iris/handle/10665/250584

We are enthusiastic about promoting this evidence–informed, locally derived intervention model to all potential interdisciplinary professional workers in community–based end–of–life care. Hopefully, we can have a competent task force if the ICEST model becomes popular or regularized.

The ICEST model and this guidebook are the co–creation of many stakeholders. We wish to thank the Hong Kong Jockey Club Charities Trust for initiating and supporting this Project. We would also like to express our gratitude to all the advisory committee members who offered us valuable and constructive advice that drives continuous improvements in our service model. Special thanks are extended to all patients, family members, and volunteers who participated in this service and offered their precious time to help us evaluate our model. We are also indebted to the colleagues of our NGO partners: The Haven of Hope Christian Service, The Hong Kong Society for Rehabilitation, SKH Holy Carpenter Church District Elderly Community Centre and St. James' Settlement, who participated actively in the service design, implementation, evaluation, and consolidation of practice wisdom.

Professor Allan Kellehear[2], our keynote speaker of the JCECC International Conference 2017, proposed that end–of–life care is everyone's responsibility. I sincerely invite you to join this mission, supporting those who are touched by terminal illnesses!

Professor Chow Yin Man, Amy

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2 Kellehear A. (2013) Compassionate communities: end-of-life care as everyone's responsibility. *QJM, 106*(12):1071-5. doi: 10.1093/qjmed/hct200.

ABOUT THE JOCKEY CLUB END OF LIFE COMMUNITY CARE PROJECT ("JCECC")

Hong Kong is facing a rapidly ageing population, and the number of elderly suffering from terminal illnesses has also escalated correspondingly. In view of the growing demand for end-of-life care services in the community, The Hong Kong Jockey Club Charities Trust approved a total of HK$255 million to initiate the "Jockey Club End-of-Life Community Care Project" (JCECC). Launched in 2016, the six-year project aims at improving the quality of end-of-life care, enhancing the capacity of service providers, as well as raising public awareness.

JCECC is a multi-disciplinary, multi-institutional and cross-sectoral collaboration to help enhance end-of-life care in Hong Kong with special emphasis on the interface between social and medical systems. Service models are being developed and shaped to provide holistic support to terminally-ill elders in the community and elderly homes. The goal is to enable the city's older people to have informed choices of care and have an improved quality of life.

The Trust's partners in JCECC are The University of Hong Kong Faculty of Social Sciences, The Chinese University of Hong Kong Jockey Club Institute of Ageing, Hong Kong Association of Gerontology, Haven of Hope Christian Service, The Hong Kong Society for Rehabilitation, St James' Settlement, and S.K.H. Holy Carpenter Church District Elderly Community Centre.

For more information: http://www.JCECC.hk/

Initiated and Funded by:

The Hong Kong Jockey Club Charities Trust

Partners:

香港中文大學 賽馬會老年學研究所 CUHK Jockey Club Institute of Ageing

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Your comments about how to improve this manual are welcomed. Should you have questions or comments, please feel free to contact the JCECC HKU Team at jcecc@hku.hk.

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We would like to express our gratitude to all team members of our NGO partners: The Haven of Hope Christian Service, The Hong Kong Society for Rehabilitation, SKH Holy Carpenter Church District Elderly Community Centre and St. James' Settlement, who participated actively in our ICEST buiding workshops and the guidebook review process, and offered their valuable comments to make this guidebook possible. Below is a list of contributors from our NGO partners who have joined our ICEST model building sessions and/or provided us their valuable comments on the ICEST guidebooks[3]:

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Last but not least, we would also like to thank all organisations and parties which allowed us to share the external hyperlinks of their valuable electronic resources and information in this manual.

HOW TO USE THIS GUIDEBOOK

TARGET AUDIENCE AND AIMS

This guidebook is intended to be used by professional workers in the Integrated Community End–of–Life Care Support Team ("ICEST"). The guidebook provides the necessary information about the ICEST model that professional workers require to be able to implement the ICEST model in community care initiatives in Hong Kong.

ORGANISATION OF THIS GUIDEBOOK

The guidebook comes in two volumes. Volume One introduces the theoretical background, development process, and ICEST care pathway. It also provides comprehensive and practical information on how to implement the first three steps in the ICEST care pathway. The contents include:

- Background to the development of ICEST;
- Summary of the ICEST care pathway;
- The 1st step of ICEST care pathway: **Identify** — client identification, referral, and engagement;
- The 2nd step of ICEST care pathway: **Assess** — standardised assessment on holistic needs of people at EoL and their community carers using need–stratifying indicators; and
- The 3rd step of ICEST care pathway: **Plan** — Person–centred care planning process that engages clients in the planning process, case conceptualisation, and care delivery with the stepped–care model.

Volume Two focuses on the fourth step in the ICEST care pathway — **Intervene**. This volume includes clinical guidelines on evidence– and needs–based interventions for people at EoL and their community carers. Intervention recommendations are presented separately for people at EoL, their community carers and families, using a systems approach.

PRACTICAL TIPS ON USING THIS GUIDEBOOK

Volumes One and Two should be read side–by–side to obtain a comprehensive understanding of the ICEST model and how it is implemented. However professional workers must receive further instruction by qualified trainers about how to deliver the ICEST model, before they are able to successfully implement it in their service setting.

Throughout this guidebook, practical tips are signposted to provide readers with key points or reminders regarding implementation of the guidelines. The electronic version of the guidebooks also has embedded internet links to assist readers to navigate readily to relevant sections. Internet links are inserted into the section headings in the table of contents so that readers can go directly to the respective section by clicking on the section head. Inside the text, readers will also see a symbol "►" signifying internal links. Readers can always return to the table of contents and important summary tables by clicking on the link at the bottom of each page.

RELATED ICEST GUIDEBOOKS/MANUALS

ICEST is an interdisciplinary team, consequently multiple guidebooks have been developed targeting the different ICEST members. Apart from the guidebook for professional workers, there are guidebooks for support care workers, and volunteer coordinators. Below is a list of the guidebooks published on ICEST and how to access them:

Guidebooks/Manuals on ICEST	Target audience	Access
Guidebook on "Integrated Community End-of-Life Support Team" (ICEST) Volume 1: Theoretical Background, Holistic Assessment & Care Planning (1st edition) (2021) [Available in both English and Chinese]	Professionals in ICEST	Downloadable at www.jcecc.hk
Guidebook on "Integrated Community End-of-Life Support Team" (ICEST) Volume 2: Evidence- and Need-based Interventions (1st edition) (2021) [Available in both English and Chinese]	Professionals in ICEST	To be distributed upon training
「綜合社區安寧照顧支援隊(ICEST)支援同工實務工作指引」(2021年,第一版) (A practical guidebook for supporting care workers in the "Integrated Community End-of-Life Support Team" (ICEST)) (1st edition) (2021) [only available in Chinese]	Supporting care workers in ICEST	To be distributed upon training
「安寧義工服務發展與統籌手冊」(2021) (A guidebook on end-of-life care volunteer development and management) (2021) [only available in Chinese]	Volunteer coordinators in ICEST	Downloadable at www.jcecc.hk

Although we make every effort to offer only accurate information, we cannot guarantee that all the hyperlinks to the resources cited in the manual will work all the time and we have no control over the availability of the linked pages.

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1. BACKGROUND AND THEORY

Palliative care (including end–of–life care (EoLC)) in Hong Kong (HK) has historically been provided by healthcare professionals, mostly in hospitals. However, people at end–of–life (EoL) have been reported to spend approximately five months in the community in their last six months of life (Lau et al., 2010), and they and their carers need various support during the period that the person at EoL stay in the community. Over the last decade, there has been a growing demand in HK for community–based EoLC. This allows people at EoL to spend as much time as possible at home, in familiar circumstances, being cared for by community carers (including family (spouse, children, grandchildren), friends and/or neighbours)[4] alongside formal health services and social services in the community, as needed. Moreover, community–based EoLC is increasingly being recognised as economically– and ethically–sound person–centred best practice. To appropriately support EoLC in the community needs a novel, although challenging, approach requiring holistic care and seamless medical–social collaboration, underpinned by a change of mindset in HK (accepts a shift from medicalised to non–medicalised, person–centred care in EoLC).

In direct response to the challenges surrounding EoL care in the community, in 2016, the HK Jockey Club Charitable Trust approved HK$255 million to fund the Jockey Club End–of–Life Community Care Project ("JCECC"). The JCECC aims to improve the quality of EoL community care (EoLCC) by enhancing the capacity of service providers, and increasing public awareness of the viability and effectiveness of person–centred EoLCC. JCECC partners include the Faculty of Social Sciences, the University of Hong Kong, CUHK Jockey Club Institute of Ageing, the Association of Gerontology, the Haven of Hope Christian Service, the Hong Kong Society for Rehabilitation, SKH Holy Carpenter Church District Elderly Community Centre and St. James Settlement.Given that populations are ageing globally, improving quality of life in people at EoL, the quality of the care they receive, and the capacity of their family carers to care for their loved ones, and themselves, is an ongoing global concern (Gómez–Batiste et al., 2019). The National Institute for Health and Care Excellence (NICE) (2017) notes that the overarching goals of EoLC in any community setting should be to:

- enhance the quality of life of people at EoL[5], and their informal community carers[6];
- provide (holistic) care which is aligned with the needs and preferences of the person at EoL, and their community carers;
- increase the length of time spent in their preferred place of care; and
- reduce unnecessary (and often unplanned, emergency) hospital admissions.

The main approach in achieving these goals is coordinating the care provided by healthcare providers and service providers in the community (palliative care specialists, non–palliative care specialists, and other health and social professionals in the community) systematically, and placing the person at EoL, and their community carers, at the centre of care decisions (NICE, 2017)

4 Community (informal, unpaid, untrained) carers cannot be always assumed to be family. Some people at EoL may be able to rely on several generations of family to assist them, however others may have only a spouse (who may be elderly and/ or unwell). Others may have neither spouse nor close family members, and may need to rely on more distant family (siblings, nieces, nephews), friends or even neighbours.

5 The description 'people at end-of-life' is used in preference to 'patient'. 'Patient' has connotations of medicalisation and passive receipt of care. This is counterintuitive to the aims of EoLCC, which is about person-centred care, empowerment, dignity, independence and individual choice at EoL

6 Community carers is used as a broad term in this manual to reflect those people providing informal care in the community to the person at EoL. This may reflect family members (spouse, children, siblings, nieces and nephews), friends and/or neighbours

1.1 THE DEVELOPMENT OF ICEST

Integral to the success of the JCECC Project is the **Integrated Community End–of–life Care Support Team (ICEST)**. The notion of this team evolved from the consolidated learnings from four service models piloted during the first three years of the JCECC project. The notion of ICEST embraces the strengths identified from each pilot service model, layered with advances in understanding about the EoL journey, the role of community carers, as well as EoL service content and delivery. Developing the ICEST model has been an evidence–driven, stakeholder–focused participatory process. This process was informed by a systematic literature review, evaluation of findings from the pilot study, and consultations with key stakeholders. Stakeholders included representatives of the non–government organisation (NGO) project partners involved in the pilot project, representatives of HK Food and Health Bureau (FHB), HK Labour and Welfare Bureau (LWB), HK Hospital Authority (HKHA), and the HK Social Welfare Department (SWD) (**Figure 1.1**).

Figure 1.1 Elements involved in developing the ICEST model

1.2 GOAL AND FEATURES OF ICEST

The ultimate goal of developing the ICEST model has been to establish a viable and effective service in holistic community–based EoLC, that could become a reference standard for EoLCC in HK, and more broadly. The aims of the ICEST model were to improve quality of life, not only for people living in the community who had a terminal illness (people at EoL), but also their informal community carers (which could variously include family members, friends, neighbours). The ICEST model is founded on respecting people's choices of place and type of care provided at EoL, and reducing unnecessary (and often unplanned, emergency, preventable) hospital admissions by empowering and supporting people at EoL, and their community carers, to make informed healthcare and lifestyle choices.

The ICEST model embraces the core features of:

1. A unified and standardised model of care
2. Filling gaps (bridging) between available services
3. Seamless collaboration between ICESTs and existing services
4. Need–based targeted interventions
5. Rigorous evidence on the effectiveness, process, and cost–effectiveness

1.2.1 A unified and standardised model of care

In the first three years of the JCECC Project, four community–based EoLC service models were tested:

1. the "enhanced community–based health care model" of the Haven of Hope Christian Service (the Hospice at Home Programme);
2. the "family capacity building model" adopted by the St. James' Settlement (the Cheering@Home End–of–Life Care Services);
3. the "non–cancer patient capacity–building model" of the Hong Kong Society for Rehabilitation (the "Life Rainbow" End–of–Life Care Services); and
4. the "community capacity–building model" adopted by the S.K.H. Holy Carpenter Church District Elderly Community Centre (the "Hospice in Family" Home Care Support Services).

A standardised evaluation framework was applied by the JCECC Project team to identify the effective components from each service model. These components formed the backbone of the ICEST model, and are broadly 4 categorized as the "3–Ps interventions": **P**hysical needs, **P**sychosocial–spiritual needs, and **P**ractical needs (**Figure 1.2**).

Figure 1.2 The components of the ICEST model

The ICEST model is delivered by multidisciplinary teams, comprising professional staff (social workers (SW), nurses (N), supporting care workers (SCW)), and trained volunteers (V). This team composition has been shown to be the most effective in delivering the 3–Ps interventions.

1.2.2 Filling gaps (bridging) between available services

There are no specialised community services in HK that provide home–based support for people at EoL, and their informal carers, to face the multi–faceted challenges that lie ahead of them. The closest SWD sub–vented services that provide community–based supports, are for frail elders. These include the Enhanced Home and Community Care Services (EHCCS), the Integrated Home Care Services (IHCS) for frail cases, the Home Care Service for Persons with Severe Disabilities (HCSPSD) and the Community Care Service Voucher (CCSV). These services focus on meeting frail elders' practical and physical needs, and they usually have long waiting periods which are likely to exceed the life expectancy of most people with a terminal illness.

If a hospital–based medical team considers that an inpatient has a high need for post–discharge rehabilitation, personal and/or home care services, he/ she might be referred to the Integrated Discharge Support Program for Elderly Patients (IDSP) or Community Nursing Service (CNS). These time–limited services focus on meeting the short–term needs of people recently–discharged from hospital, who have rehabilitation potential. People with terminal illnesses are usually considered as low priority for rehabilitation, and thus they would not be prioritised.

Moreover, psychosocial and spiritual care which may be important at EoL is not addressed by these services. People who have only a short time to live may require timely, specialised support to optimize their quality of life and wellbeing, and that of their informal community carers. Hospital–based medical Social Services (MSS) workers can provide psychosocial support, but this service is mainly provided in hospital, to admitted patients. Once people at EoL are discharged from hospital to the community, service options change. If they or their community carers require psychosocial support, they can approach Integrated Family Services Centres (IFSC) or even the District Elderly Community Centres (DECC) for assistance. However in most instances, these services are not sufficiently specialised to meet their particular needs.

Nevertheless, ICEST does not offer palliative care. Instead, its remit is to identify and bridge gaps in current community services by providing unique options, such as:

- Playing a supportive role in symptom management through psychoeducation on symptom management at home, and faciliting effective and timely communication between medical teams, people at EoL and their community carers;
- Acting as a community resource coordinator to assist people at EoL to access the assistance they, or their community carers, require to enable them to stay at home for as long as possible; and/or
- Providing specialised psychosocial–spiritual care which aims to promote resilience, and facilitate dignified experiences for people at EoL, and their community carers.

1.2.3 Seamless collaboration between ICESTs and existing services

A core function of ICEST is to collaboratively identify and bridge gaps between existing services to ensure that people at EoL, and their community carers' needs are addressed as comprehensively and seamlessly as possible. This is done on a case–by–case basis. Not only does this relieve the stresses on clients that unfilled service gaps might impose, but it also improves overall service quality, and sets standards for collaboration between services in other sectors. **Figure 1.3** outlines the proposed collaboration between ICEST, HKHA services and community services provided by the SWD. If people at EoL meet the criteria for any HKHA service, or existing community services, shared care can be provided collaboratively without overlapping the resources, with ICEST service being an extra layer of specialised EoLC in the community

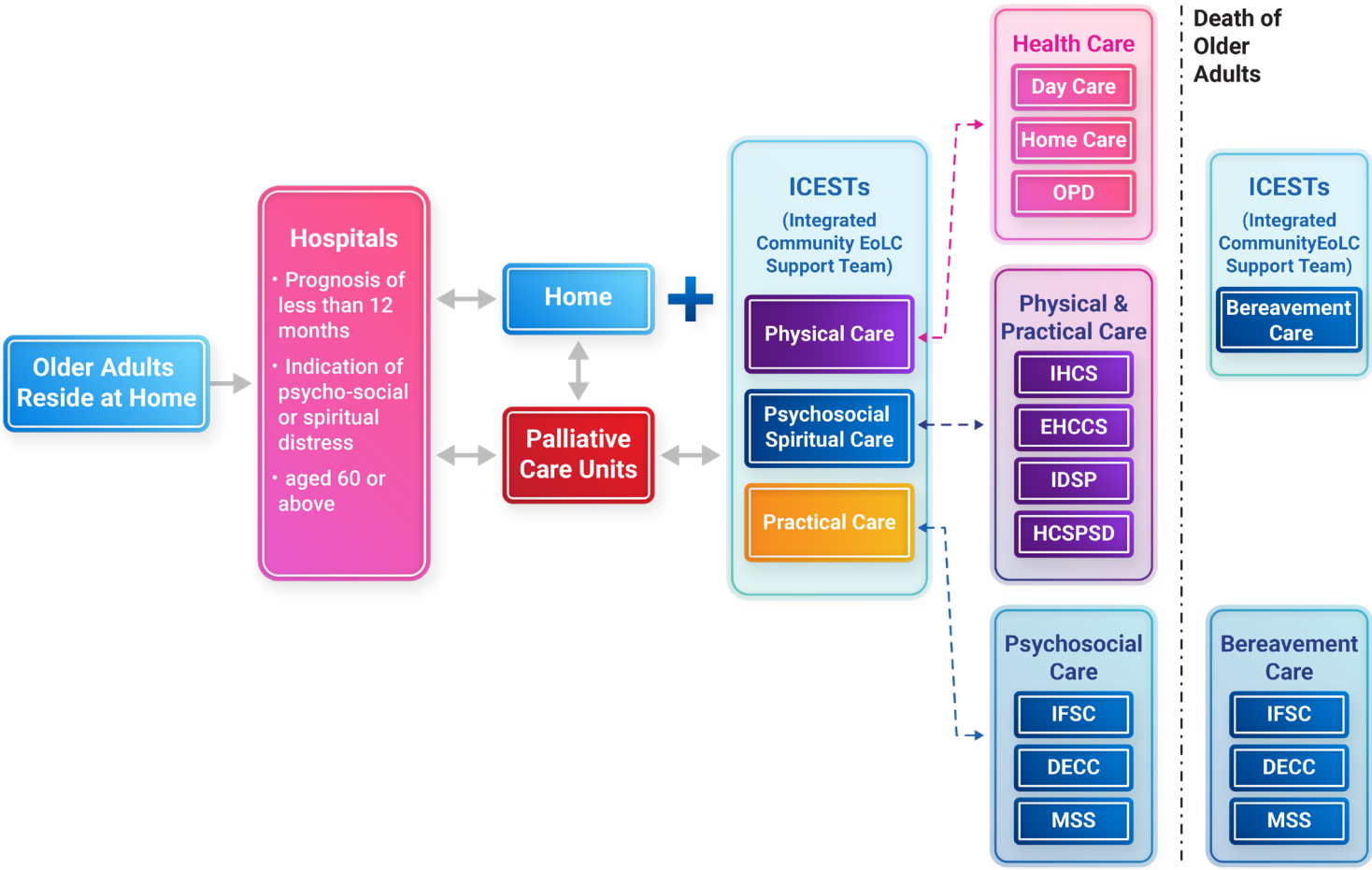


Figure 1.3 Collaboration between ICESTs and existing services[7] .

7 IHCS=Integrated Home Care Services; EHCCS=Enhanced Home and Community Care Services; CCSV=Community Care Service Voucher; HCSPSD=Home Care Service for Persons with Severe Disabilities; IFSC=Integrated Family Services Centre; DECC=District Elderly Community Centre; MSS=Medical Social Services

1.2.4 Need-based targeted interventions

Needs–based, person–centred palliative care interventions have gained growing attention in the last few decades. It is increasingly accepted that people at EoL can experience variable and often unpredictable disease trajectories, which directs their need for palliative care over the course of the disease (Irish Association for Palliative Care, 2018; McCallum, 2018; Palliative Care Australia, 2005). In order to provide holistic, timely, integrated EoLCC services, ICEST embraces a person–centered approach to identify and meet the needs of clients. This generally requires comprehensive and iterative assessments, and complex interventions which can involve multiple interacting service components. To identify these components often requires the application of relevant behaviour change theories, structured needs identification approaches and assessment of a range of expected outcomes (Moore et al., 2015). Outcomes can involve changes in attitude, value, emotion, and behavior. Therefore, the term "theories of change" is used to refer to making clear connections between a given intervention and its outcomes.

To facilitate the development and delivery of personalised, needs–based, targeted interventions for people at EoL and their community carers, a stepped care model has been adopted in ICEST. This uses a needs–stratifying screening and assessment tool (3–P assessment) which applies threshold values to determine the individual level of need in each of the 3–P domains (Physical, Practical, Psychosocial). These thresholds were derived during the JCECC pilot project. ICEST services are provided according to the type and level of client need. Given the unpredictable illness trajectories and the relatively short life expectancies of people at EoL, targeted evidence–based interventions have to be provided in a precise fashion, not only at the right moment, but also in the right way for each situation, to ensure positive outcomes within the shortest time possible, for all involved.

Recommendations for ICEST interventions are mostly based on:

- Evidence– or consensus—based clinical practice guidelines in palliative and EoLC, which are identified using the search strategy in the Clinical Decision Support Tool development study (van Vliet, Harding, Bausewein, Payne, & Higginson, 2015). Where indicated, hand–searching is then undertaken in retrieved practice guidelines for evidence for specific techniques and strategies; and/or
- Systematic reviews included in the National Consensus Project Clinical Practice Guideline 4th edition (Ferrell, Twaddle, Melnick, & Meier, 2018).

If recommendations for specific care domains are not identified from these sources, then further searching is undertaken to identify other sources of evidence (ideally systematic reviews, and randomised controlled trials (RCTs)) to inform interventions.

Recommendations are then adapted, if required, to fit clients' needs, contexts and circumstances, and the capacity of ICEST workers, without changing the core principles/rationales of the original recommendations. Specialised medical/ pharmaceutical interventions are not implemented by ICEST; and nursing care is excluded, except for general health care.

1.2.5 Rigorous evidence on the effectiveness, process, and cost-effectiveness

An existing evaluation framework was adopted to generate evidence on the inputs, outputs, outcomes and impacts of the ICEST model, and to enable continuous monitoring and improvement. This framework had been developed by Deborah Rugg for the Institute of Medicine (IOM), for a large–scale U.S. President's Emergency Plan for AIDS Relief (IOM, 2014). Evidence to support evaluations was generated using mixed methods research, which combined findings from clinical assessments (to evaluate over–time changes in objective outcomes), satisfaction surveys, in–depth interviews (to evaluate subjective outcomes), and medical service utilisation information (generated post–mortem).

The 2019 evaluation findings of JCECC ICEST pilot were encouraging. They lent support to the effectiveness of the ICEST vision in alleviating physical–psychosocial–spiritual distress faced by people at EoL, easing emotional distress and burdens experienced by their community carers, and in dealing with practical problems faced by people at EoL and/or their carers. There are plans to assess the cost–benefits of the ICEST model in future evaluations. This will enhance evaluation rigor and provide further evidence around the fidelity, feasibility, and sustainability of the ICEST model. This cost–benefit analysis will be undertaken within the framework of Social Return on Investments (SROI) (The SROI Network, 2012), and will include surveys of relevant community stakeholders (referral agencies and/or collaborating hospital partners) and process evaluations conducted in conjunction with ICEST staff.

2. THE ICEST CARE PATHWAY

The four steps in the ICEST care pathway were adapted from the central processes of the Gold Standards Framework (The Gold Standards Framework, 2016). The original pathway consisted of three steps (Identify–Assess–Plan). The fourth step, Intervene, was added to complete the care pathway of the ICEST model (**Figure 2.1**). Concrete actions involved in each of the four steps are outlined in **Figure 2.2**.

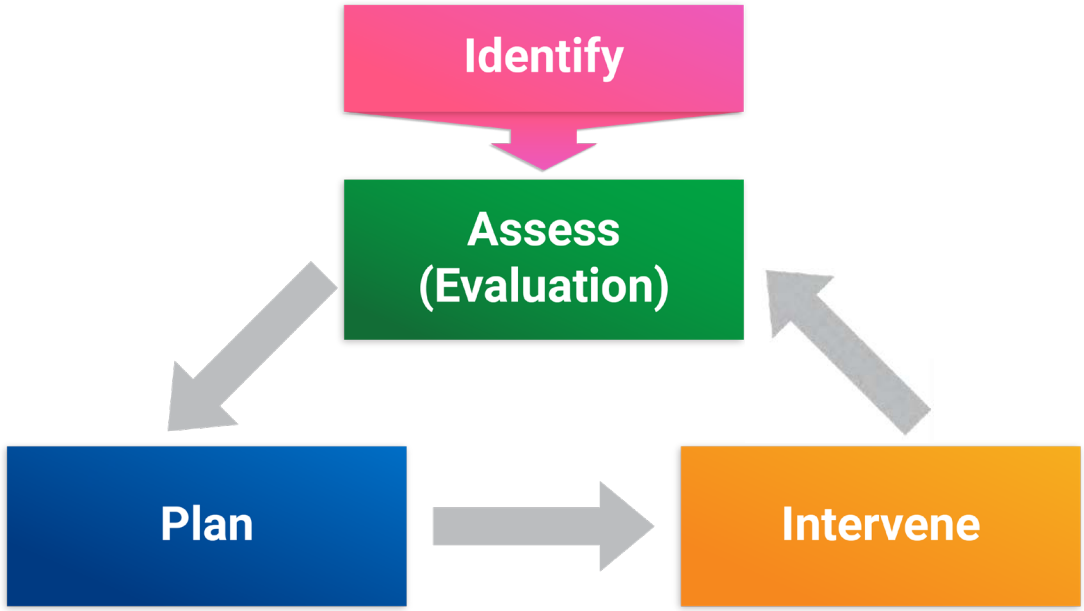


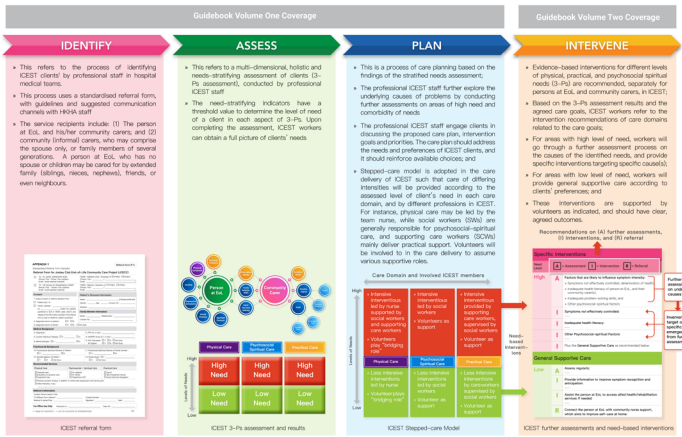
Figure 2.1 The ICEST model care pathway

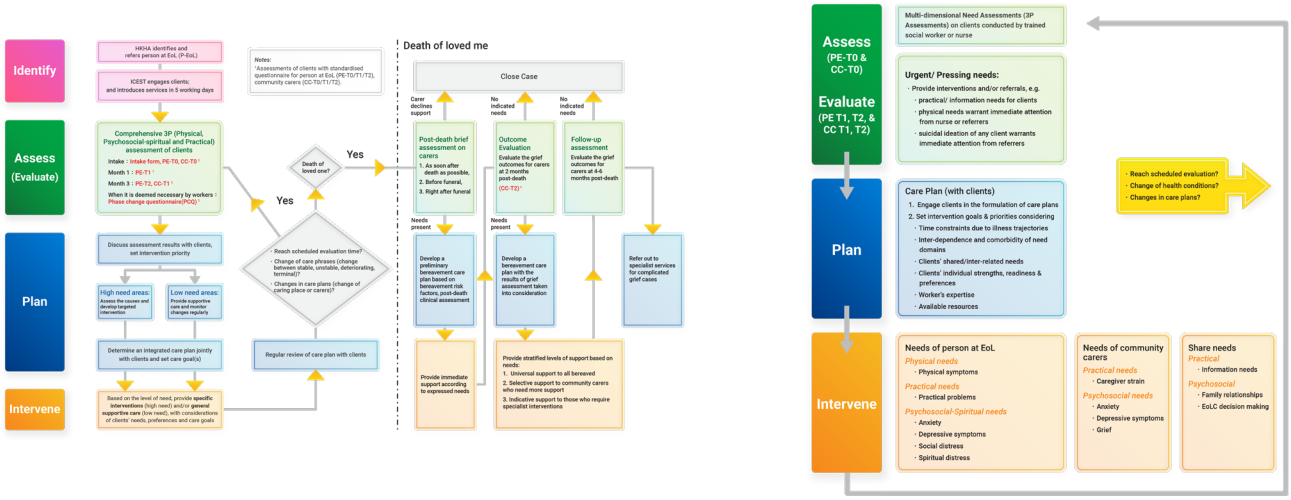
2.1 THE "ASSESS-PLAN-INTERVENE" CYCLE

The "assess–plan–intervene" steps form a cycle of service delivery which is proactively and regularly revisited across the EoL journey. Reassessment alerts the ICEST team to clients' changing needs, and ensures that appropriate needs–based interventions can be provided in a timely manner. Re–assessment also provides data to evaluate the effect of earlier interventions.

Figure 2.3 outlines the overall implementation flow of the ICEST model. **Figure 2.4** shows the detailed clinical care pathway upon case intake. These figures show how the "assess–plan–intervene" cycle is enacted throughout the service delivery period after specific triggering situations (e.g. evaluation time window, change of care phase, changing client needs, issues identified by healthcare practitioners etc.). This cycle includes the bereavement stage.

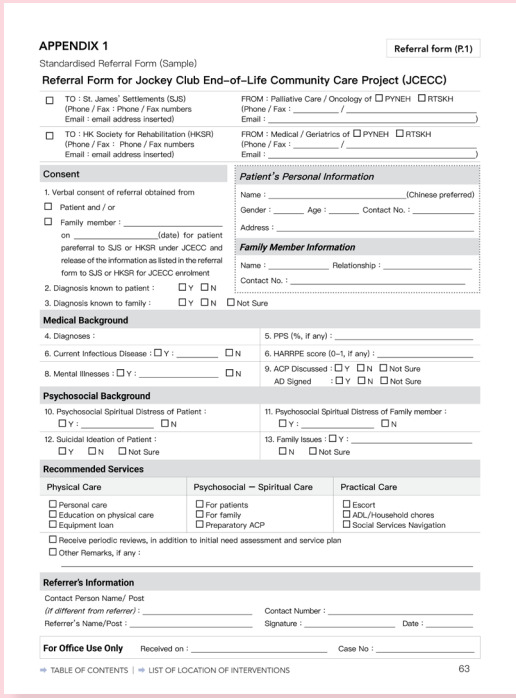
The **guidebook volume one** will focus on the first three steps — **identify**, **assess**, and **plan** whereas the **guidebook volume two** will elaborate on the fourth step— **intervene**.





IDENTIFY

- This refers to the process of identifying ICEST clients[8] by professional staff in hospital medical teams.
- This process uses a standardised referral form, with guidelines and suggested communication channels with HKHA staff
- The service recipients include: (1) The person at EoL and his/her community carers; and (2) community (informal) carers, who may comprise the spouse only, or family members of several generations. A person at EoL who has no spouse or children may be cared for by extended family (siblings, nieces, nephews), friends, or even neighbours.



APPENDIX 1

Referral form (P.1)

Standardised Referral Form (Sample)

Referral Form for Jockey Club End-of-Life Community Care Project (JCECC)

☐ TO : St. James' Settlements (SJS) (Phone / Fax : Phone / Fax numbers Email : email address inserted)

FROM : Palliative Care / Oncology of ☐ PYNEH ☐ RTSKH (Phone / Fax : ____ / ____ Email : ____)

☐ TO : HK Society for Rehabilitation (HKSR) (Phone / Fax : Phone / Fax numbers Email : email address inserted)

FROM : Medical / Geriatrics of ☐ PYNEH ☐ RTSKH (Phone / Fax : ____ / ____ Email : ____)

Consent

1. Verbal consent of referral obtained from
☐ Patient and / or
☐ Family member : ____ on ____(date) for patient pareferral to SJS or HKSR under JCECC and release of the information as listed in the referral form to SJS or HKSR for JCECC enrolment
2. Diagnosis known to patient : ☐ Y ☐ N
3. Diagnosis known to family : ☐ Y ☐ N ☐ Not Sure

Patient's Personal Information

Name : ____(Chinese preferred)
Gender : ____ Age : ____ Contact No. : ____
Address : ____

Family Member Information

Name : ____ Relationship : ____
Contact No. : ____

Medical Background

4. Diagnoses :
5. PPS (%, if any) : ____
6. Current Infectious Disease : ☐ Y : ____ ☐ N
6. HARRPE score (0–1, if any) : ____
8. Mental Illnesses : ☐ Y : ____ ☐ N
9. ACP Discussed : ☐ Y ☐ N ☐ Not Sure
AD Signed : ☐ Y ☐ N ☐ Not Sure

Psychosocial Background

10. Psychosocial Spiritual Distress of Patient : ☐ Y : ____ ☐ N
11. Psychosocial Spiritual Distress of Family member : ☐ Y : ____ ☐ N
12. Suicidal Ideation of Patient : ☐ Y ☐ N ☐ Not Sure
13. Family Issues : ☐ Y : ____ ☐ N ☐ Not Sure

Recommended Services

Physical Care	Psychosocial – Spiritual Care	Practical Care
☐ Personal care ☐ Education on physical care ☐ Equipment loan	☐ For patients ☐ For family ☐ Preparatory ACP	☐ Escort ☐ ADL/Household chores ☐ Social Services Navigation

☐ Receive periodic reviews, in addition to initial need assessment and service plan
☐ Other Remarks, if any : ____

Referrer's Information

Contact Person Name/ Post *(if different from referrer)* : ____ Contact Number : ____
Referrer's Name/Post : ____ Signature : ____ Date : ____

For Office Use Only Received on : ____ Case No : ____

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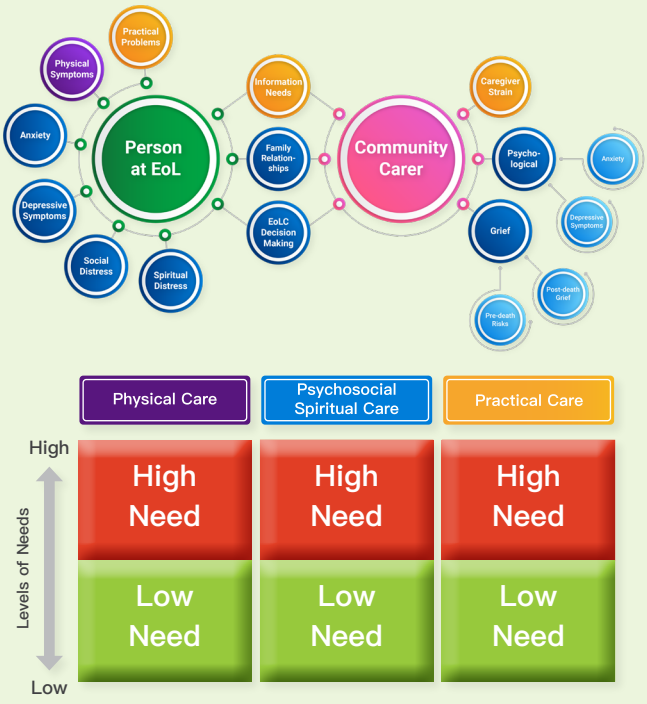
ICEST referral form

ASSESS

- This refers to a multi-dimensional, holistic and needs-stratifying assessment of clients (3-Ps assessment), conducted by professional ICEST staff
- The need-stratifying indicators have a threshold value to determine the level of need of a client in each aspect of 3-Ps. Upon completing the assessment, ICEST workers can obtain a full picture of clients' needs



ICEST 3-Ps assessment and results

Figure 2.2 Actions in each step of ICEST care pathway

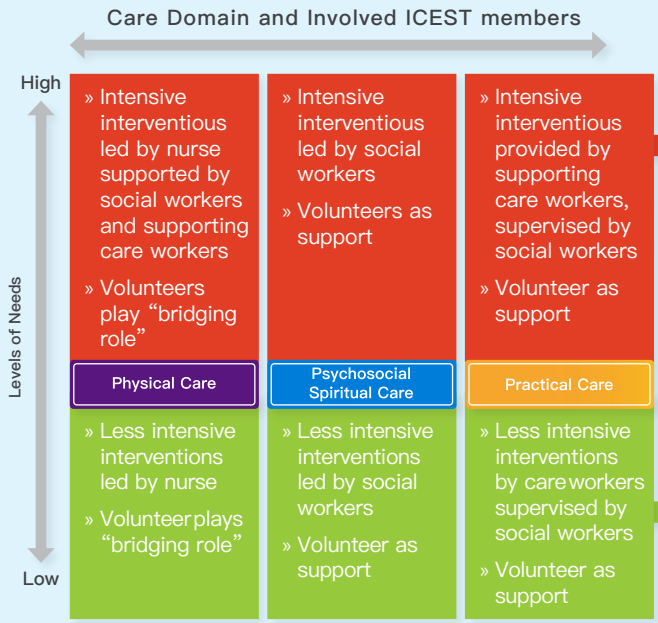
8 This terms is used for ease of reading, to refer to the person at EoL and his/her informal carers in the community

Guidebook Volume One Coverage

Guidebook Volume Two Coverage

PLAN

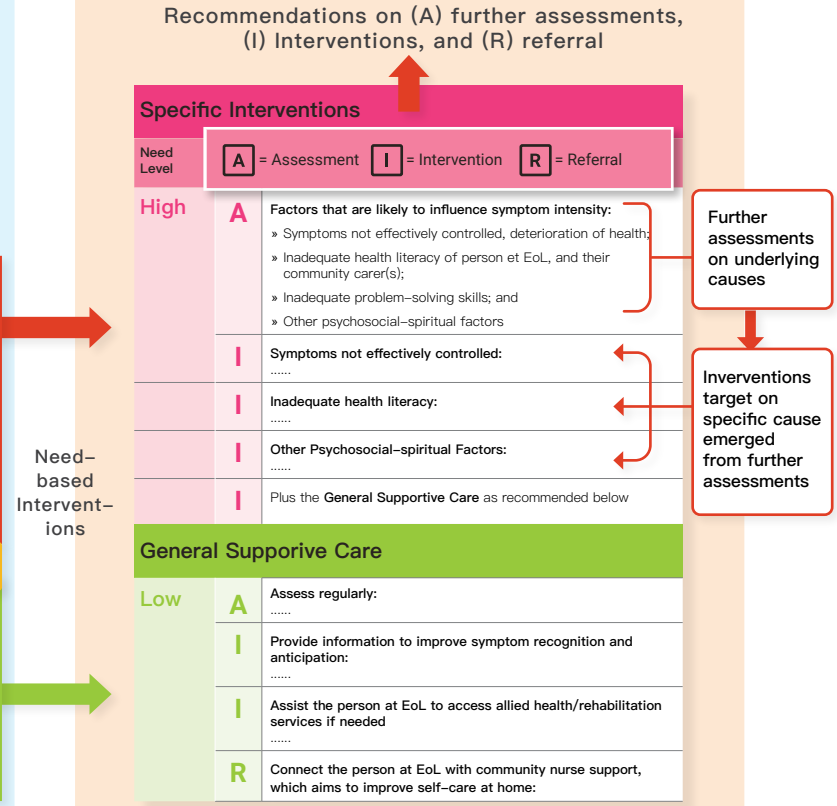
- This is a process of care planning based on the findings of the stratified needs assessment;
- The professional ICEST staff further explore the underlying causes of problems by conducting further assessments on areas of high need and comorbidity of needs
- The professional ICEST staff engage clients in discussing the proposed care plan, intervention goals and priorities. The care plan should address the needs and preferences of ICEST clients, and it should reinforce available choices; and
- Stepped–care model is adopted in the care delivery of ICEST such that care of differing intensities will be provided according to the assessed level of client's need in each care domain, and by different professions in ICEST. For instance, physical care may be led by the team nurse, while social workers (SWs) are generally responsible for psychosocial–spiritual care, and supporting care workers (SCWs) mainly deliver practical support. Volunteers will be involved to in the care delivery to assume various supportive roles.



ICEST Stepped–care Model

INTERVENE

- Evidence–based interventions for different levels of physical, practical, and psychosocial spiritual needs (3–Ps) are recommended, separately for persons at EoL and community carers, in ICEST;
- Based on the 3–Ps assessment results and the agreed care goals, ICEST workers refer to the intervention recommendations of care domains related to the care goals;
- For areas with high level of need, workers will go through a further assessment process on the causes of the identified needs, and provide specific interventions targeting specific cause(s);
- For areas with low level of need, workers will provide general supportive care according to clients' preferences; and
- These interventions are supported by volunteers as indicated, and should have clear, agreed outcomes.



ICEST further assessments and need–based interventions

Figure 2.2 (Continued) Actions in each step of ICEST care pathway

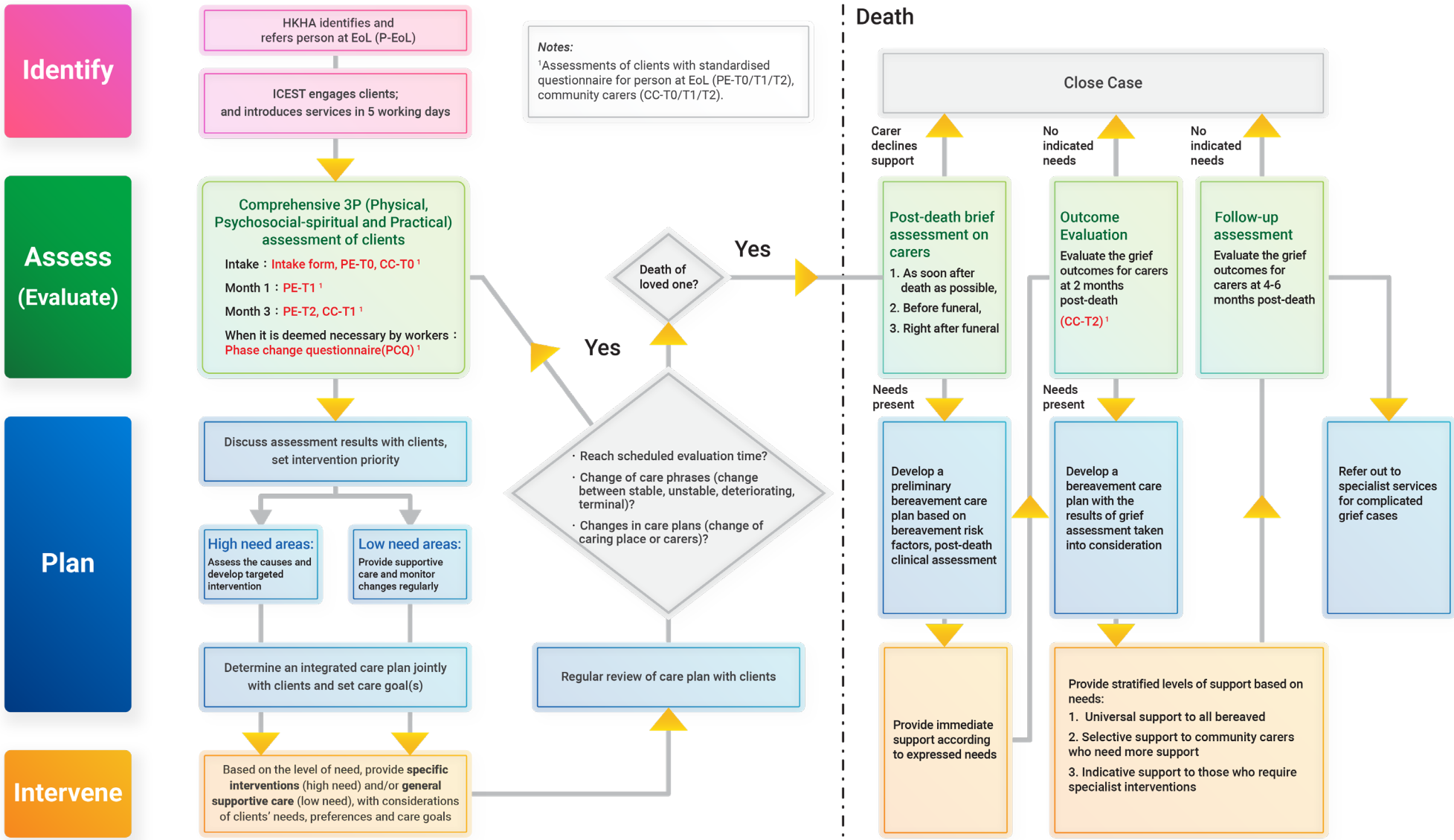


Figure 2.3 Flowchart of ICEST model Implementation

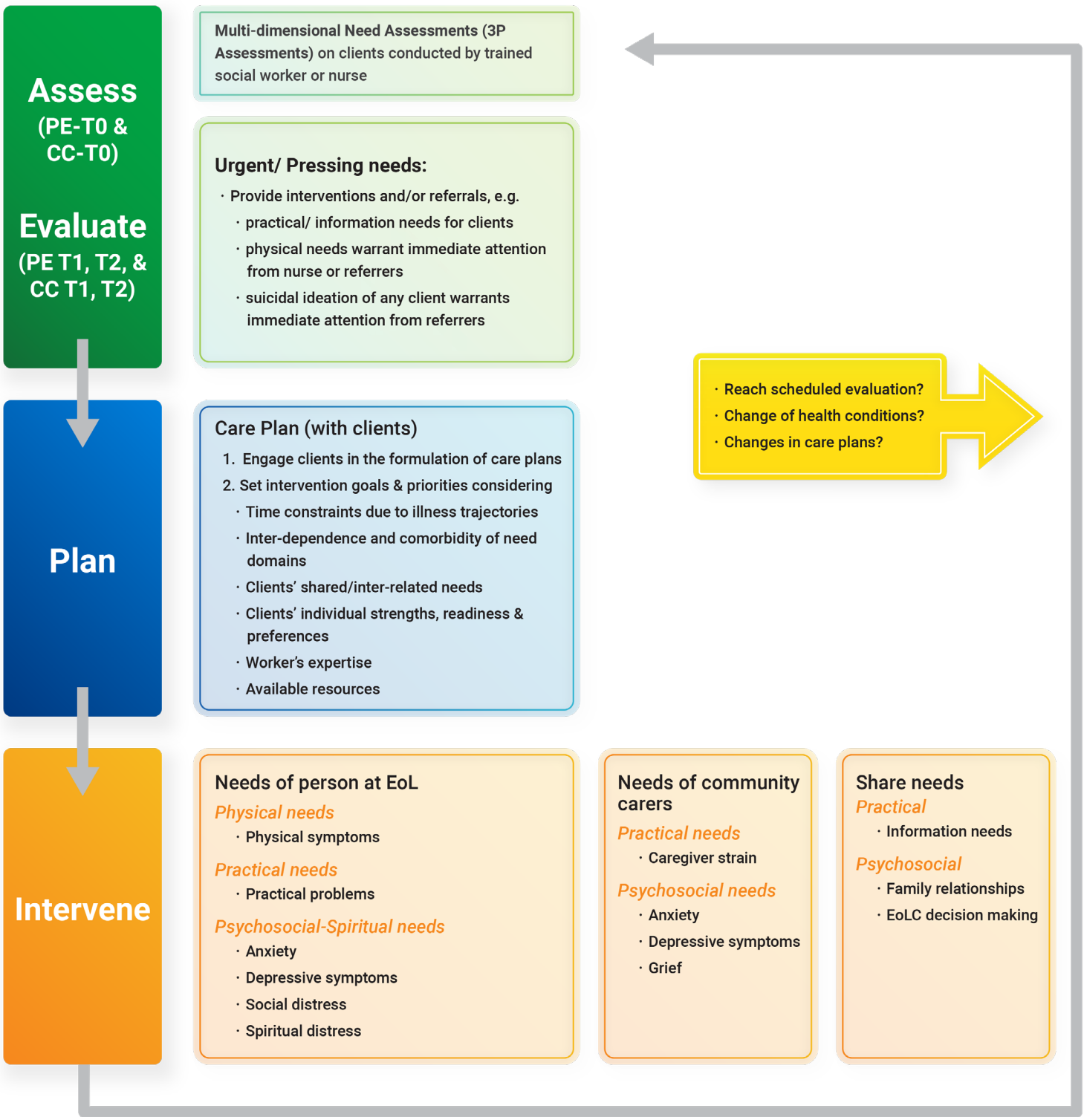


Figure 2.4 ICEST clinical care pathway upon case intake[9]

9 The 3-P needs are usually inter-dependent. For example, solving or alleviating problems in the physical and practical domains may reduce the psychosocial spiritual needs. For the shared needs, workers can consider joint interventions as appropriate. Prior consent from all relevant parties should be solicited.

3. IDENTIFY — CLIENT IDENTIFICATION AND ENGAGEMENT

Client identification, referral, and engagement are the core tasks in the "Identify" step of ICEST care pathway. This process is facilitated by a standardised referral system and communication channels agreed with hospital partners, and a structured engagement process.

3.1 STANDARDISED CLIENT IDENTIFICATION AND REFERRAL SYSTEM

A standardised referral system (**Figure 3.1**) has been agreed with the HKHA by the ICESTs under JCECC. This references the 6th edition of the "Gold Standards Framework Proactive Identification Guidance" (GSF PIG) (The Gold Standards Framework, 2016).

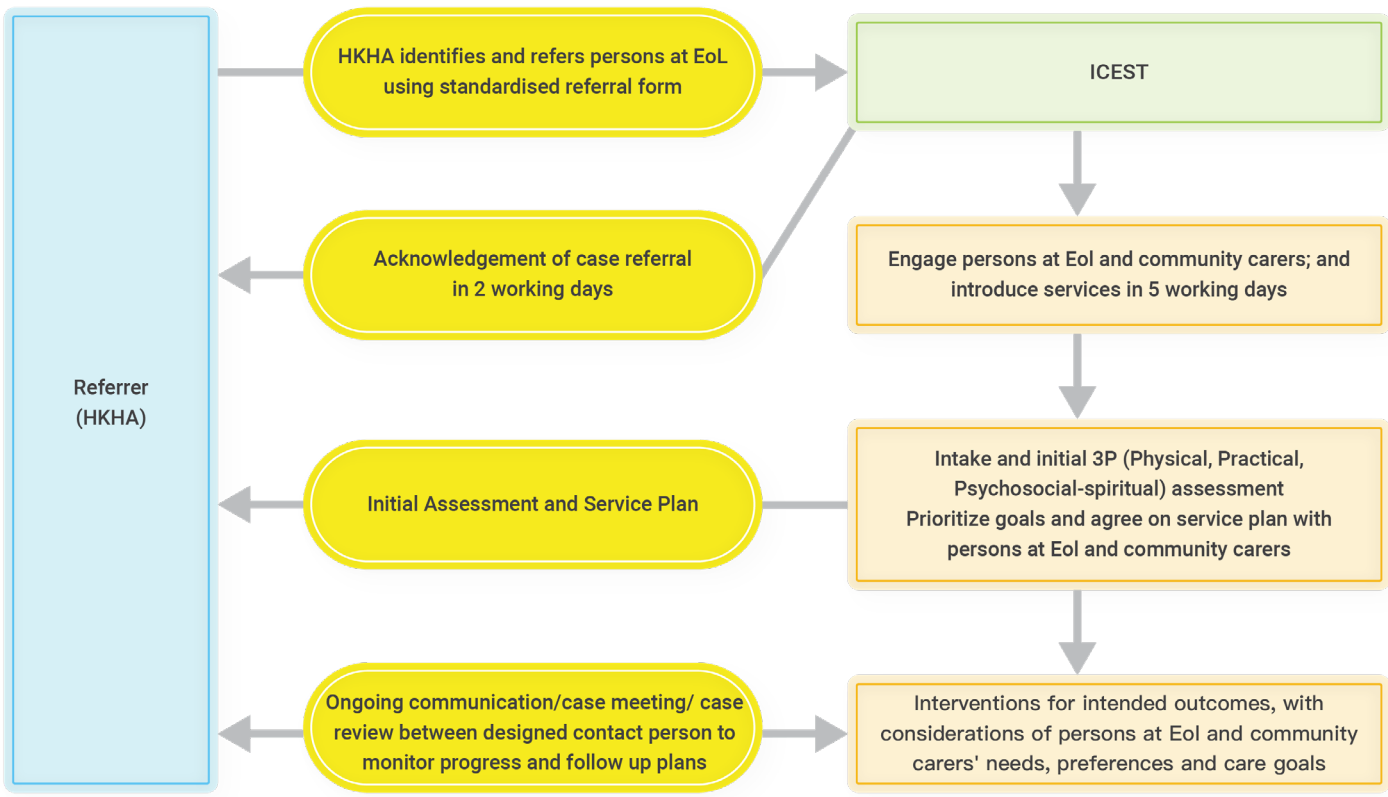


Figure 3.1. Referral and communication system between HKHA and ICEST

3.2 CRITERIA FOR REFERRAL

People who are eligible for ICEST support are those who:

- Are referred by HKHA;
- Are diagnosed with a terminal illness (with a prognosis of 12 months or less);
- Exhibit evidence of psycho–social–spiritual distress;
- Indicate a preference of care at community;
- Are preferably aged 60 years or older; and
- Are not receiving services from EHCCS, IHCS, Day Care Centres for the Elderly (DE), IDSP, CCSV, or similar services.

3.3 REFERRAL FORM

A sample standardised referral form used by the ICESTs run by St. James' Settlement and the HK Society for Rehabilitation (►**Appendix 1, p.63**) was collaboratively designed with HKHA. This includes common criteria for referral to palliative care services (Hui et al., 2016; McCusker et al., 2020):

- Verbal consent for referral;
- Diagnosis, other physical and mental conditions of concerns;
- The functional abilities of the person at EoL, coupled with his/her care requirements (Palliative Performance Scale (PPS) and Hospital Admission Risk Reduction Profile for the Elderly (HARRPE));
- Psychological distress (exhibited by the person at EoL or his/her community carers), including suicidal ideation;
- Clients express the need for EoL planning (where there is no Advance Directive (AD)/Advance Care Plan (ACP)); and
- There is a clear need for physical, psychosocial–spiritual, and/or practical care that is not met by existing services.

At the same time, the following communication channels are recommended to facilitate care coordination with healthcare teams:

Practical Tips

Effective communication channels with healthcare teams

- Designated contact persons from the ICEST team and the ward are nominated to ensure continuity of services;
- After the person at EoL has been accepted by ICEST, the ICEST team sends the corresponding ward an initial assessment and service plan (►**Appendix 2, p.65**); and
- Regular case meetings or case reviews are established to monitor individual case progress as well as improve service quality, and identify service gaps.

3.4 ENGAGEMENT PROCESS

When clients are referred to ICEST, brief telephone contact is made, where possible, with the person at EoL, and where not possible, with one or more of his/her community carers. Contact comes from a trained SW or nurse within five working days of referral. The contact should include the following communication (**Table 3.1**):

Practical Tips

Table 3.1 Communication in engagement process

Purposes	Examples
State purpose of contact	» Refer to the referrer and clarify reasons of referral, e.g. *"I am XXX from organisation YYY. Dr X/ Nurse Y from Hospital AA is very concerned about your well-being, and that of your family. They hope to better support you after your discharge from hospital, thus they have referred you to our organisation.";* *「我係YYY機構嘅XXX，AA醫院嘅X醫生/Y護士好關心您同您家人喺出院後嘅情況，希望可以加強對您哋嘅支援，所以將您哋轉介咗俾我哋機構。」* » Sensitively but honestly communicate the service objectives, service coverage and content, e.g: *"We work closely with XX (referrer) to provide additional support to people with serious illness and their family, besides that provided by the hospital. We provide physical, emotional, and practical support to maintain your quality of life. We also provide support to your carers, volunteer visitors, etc.";* *(我哋同XX (轉介單位) 緊密合作，為患有嚴重疾病嘅晚期病患者同埋家庭提供醫院以外多一重嘅支援，我哋提供身體、情緒同埋生活實際需要嘅支援，幫助你哋喺家中維持有質素嘅生活，同時為你嘅照顧者提供支援，亦有義工服務等等...)*
Build Rapport	» Express concerns and care towards people at EoL, their community carers and their family members (if they are not involved in caring), e.g. *"Dr X and Nurse Y care about your well-being and that of your family.",* *(X醫生同Y護士都好關心你同你屋企人嘅狀況。);* *"How is your (or the person at EoL's name) body doing?";* » (您（或晚期病患者姓名）宜家嘅身體點樣呀？);

Table 3.1 (Continued) Communication in engagement process

Purposes	Examples
Quick assessment	» Awareness of diagnosis and prognosis, e.g. *"What did the doctor tell you (or the person at EoL's name) about the illness?";* *"Everybody's needs are unique. We will work together with you to find out what you need, what to do first to achieve the goal";* *(醫生話您（或晚期病患者姓名）依家個病況係點樣呀？);* » Pressing needs, especially for quick-to-arrange resources or practical support *""What do you think bothers you and your carers/ family the most?";* *(您覺得宜家最困擾您同您照顧者/屋企人嘅係啲乜嘢？);*
Engage the person at EoL (and their community carers) to participate in the "joint" helping process	» Seek agreement to the helping process and emphasise their participation in the assessment (which will be done in the first visit), planning and intervention prioritisation, e.g. *"Everybody's needs are unique. We will work together with you to find out what you need, what to do first to achieve the goal";* *(每個人嘅需要都有唔同，我哋會同您哋一齊看看你哋嘅需要係乜嘢，看看做邊樣先，為(呢個目標)而努力。);* *"This is not an easy journey and we will stand by you";* *(呢條路唔易行，我哋會喺身邊一直支持您哋嘅。);* » Seek consent for the ICEST team's ongoing collaborations with the referrer, including information sharing, e.g. *"When needed, we will exchange your information with XX (referrer), aim to provide you the services you need the most. Do you mind?";* *(我哋喺有需要時會同XX (轉介單位) 交流有關你哋嘅資料，希望能提供你哋最需要嘅服務。你哋介唔介意？).*
Schedule the first visit	» *Time*: ask about the earliest convenient time to visit (as soon as possible, but preferably when the person at EoL is most alert, and/ or when community carers are present); » *Place*: preferably at home but if the person at EoL is unlikely to be discharged soon, the visit can be done at hospital with consent from the ward; and » *Information*: collect key useful information for emergency use (e.g. contact number of family members, especially those live with the person at EoL).

4. ASSESS — ASSESSING HOLISTIC NEEDS OF CLIENTS

4.1 ASSESSMENT TARGETS AND TIMELINE

In this phase, ICEST workers conduct an initial holistic assessment of client needs, as well as the level of needs. The assessment package involves an **intake form**, and **ICEST assessment questionnaires** which solicit direct responses from ICEST clients. ICEST workers can assist with completing some assessments by observation, if the person at EoL is unable, or unfit, to provide answers. Specific (and different) assessment time points are designed for people at EoL, and their community carers, to inform and review subsequent care plans. Given that people at EoL stay in the service, on average, for six months, at least three assessment time points are suggested (at service intake, 1 month and 3 months after service). Community carers are assessed twice before their loved one's death (at service intake and 3 months after service), and a grief assessment is administered two months after death. **Table 4.1** summarises the assessment time points and related questionnaires. The two follow–up assessments serve to monitor the achievement of goals over the different time periods.

Table 4.1 Overview on the assessment timelines for people at EoL and community carers[10]

Time points / Targets	First assessment	Second assessment	Third assessment
Person at EoL questionnaires (PE–T)			
Time being collected	Service intake	1 month after service	3 months after service
Questionnaire code	PE–T0	PE–T1	PE–T2
Community carers questionnaires (CC–T)			
Time being collected	Service intake	3 month after service	2 months after service
Questionnaire code	CC–T0	CC–T1	CC–T2

10 PE T0, PE T1, PE T2 are codes for person at EoL questionnaires. CC T0, CC T1, CC T2 are codes for community carer questionnaires. The complete version of questionnaires will be distributed in ICEST training courses.

4.2 ASSESSMENTS AT CRITICAL TRANSITION POINTS

Although there is a pre–set assessment schedule, ICEST workers should be aware of the importance of conducting ongoing holistic assessments throughout the disease trajectory. Repeated assessments are recommended to identify when changes in care are required (The National Institute for Health and Care Excellence [NICE], 2019). In particular, timely assessment is needed at critical transition points for people at EoL, and their community carers, related to how they cope with changes along the disease trajectory. Examples of key transition points include:

- At diagnosis of a life–limiting condition;
- When there are episodes of significant progression/exacerbation of disease;
- When significant changes occur in family/social supports;
- When there is significant change in functional status;
- On request of person at EoL and/or community carers; and
- At death.

(The National Clinical Programme for Palliative Care & HSE Clinical Strategy and Programmes Division, 2014, p. 5)

Apart from these points, discharge from hospital, and the time when the goals of treatment have changed, are also transition points which can flag the need for re–assessment (NICE, 2019). The 3–Ps assessment has been condensed into a Phase Change Questionnaire (PCQ)[11] that can be used for assessment at these critical transition points.

4.3 ASSESSMENT CONTENTS

he whole assessment involves two core parts:

1. Background information and assessment preferences; and
2. Holistic ICEST client needs assessment.

The first contact interview should cover both parts. Assessments at future contacts should mainly focus on Part 2 but may include a review of the information from Part 1 should the situation change. However, as a person approaches death, the depth of assessment should be adjusted to cover only what most concerns that person, and his/her carers, at that time.

11 The complete version of questionnaires will be distributed in ICEST training courses.

4.3.1 Background information and assessment preferences

An intake form has been designed to collect case background information (summarised in **Table 4.2**).

Table 4.2 Suggested background information

Background information	
Personal particulars	Demographics, living conditions, family composition etc.
Functional ability	» Physical impairments (e.g. hearing, vision, speech/voice) » Communication ability » Cognitive ability & mental capacity » Activity ability & balancing » Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) » Diet and ingestion status
Medical history & availability of care plan	» Diagnosis and presence of comorbidity » Awareness of diagnosis/prognosis by the person at EoL » Current treatment plan and past treatments » Current medication and drug management » Awareness, & availability, of AD and ACP
Services received	Types and times of medical and social services used in previous month

Each new case requires the completion of an intake form. The following practical tips can facilitate the ICEST workers to conduct the intake interviews:

Practical Tips

General Tips for conducting intake interviews

» Workers may consider asking family members, or friends to provide some of the required information in order to reduce the burden on the person at EoL;

» To populate the medical history and the section on care plans, workers can refer to the referral form without needing to ask more questions;

» Before commencing the assessment, workers should determine the willingness of the person at EoL and their carers, to participate in it. Workers should assure them that the purpose of the assessment is to understand their needs thoroughly, in order to develop and deliver tailored services; and

» People at EoL and their community carers should each give clear verbal consent to every assessment and this should be documented every time in the case notes.

Practical Tips

Asking about diagnosis/prognosis, existence of AD and/or ACP during intake

Sensitivity is required by ICEST workers when asking questions such as diagnosis/prognosis, or the existence of AD and/ or ACP. The workers may ask the following questions which are related to diagnosis/prognosis, and awareness of ADs and ACPS:

- ICEST workers can explore the level of awareness of the person at EoL about his/her diagnosis/prognosis by asking "Can you tell me about your illness?" (你可以講吓俾我聽你而家個病情點？).
- Regardless of the presence of AD/ ACP as indicated in the referral form, ICEST workers can explore how people at EoL and their carers understand it, by asking "Have you heard about AD/ACP from the healthcare team or somewhere else?" (醫生護士有沒有曾跟你說有關預設醫療指示/預設照顧計劃？), and "What did you know about AD/ACP?" (以你所知，預設醫療指示/預設照顧計劃是甚麼呢？).
- Where indicated, ICEST workers may consider providing education to their clients to address any misunderstandings

4.3.2 Holistic ICEST client need assessment

The standardised ICEST assessment tool consists of screening questions on **P**hysical, **P**sychosocial Spiritual, and **P**ractical care aspects (3–Ps Assessment). **Table 4.3** outlines the core assessment domains and sub–domains. This provides a framework within which the ICEST workers can assist their clients holistically to identify their needs. It also underpins discussions on planning and prioritising interventions around meeting these needs.

Table 4.3 Overview on the 3–Ps assessment domains for clients

	3–Ps Assessment Domains		
Target	**Physical**	**Psychosocial Spiritual**	**Practical**
Person at EoL	Physical symptoms (►p.38)	Anxiety (►p.39)	Practical problems (►p.43)
		Depressive symptoms (►p.39)	
		Spiritual distress (►p.40)	
		Social distress (►p.41)	Information needs (►p.43)
		Family relationships (►p.41)	
		EoLC decision making (►p.42) (Care planning and Preparatory ACP)	
Community carers	--	Anxiety (►p.44)	Caregiver strain (►p.48)
		Depressive symptoms (►p.44)	
		EoLC decision making (►p.45) (Care planning and Preparatory ACP)	
		Risks of grief (►p.46) (EoLC stage)	Information needs (►p.48)
		Grief (►p.47) (bereavement stage)	

Practical Tips

Which kind of needs should be focused first?

ICEST workers should focus first on addressing urgent needs that may warrant immediate intervention and/or referral, such as:

» practical/ information needs to maintain normal living, e.g. rehabilitation equipment loan and financial aid

» urgent physical needs requiring nursing advice, or referral to a specific service

Practical Tips

Who can administer holistic ICEST need assessment?

The ICEST assessment should be administered by trained social workers or nurses who possess good listening and communication skills, are sensitive to others' emotions, and are familiar with the rationale, construct and purpose of the ICEST assessment.

4.4 SCREENING AND ASSESSING WITH NEED-STRATIFYING INDICATORS IN 3-PS ASSESSMENT

A threshold value is applied in all need–stratifying indicators in 3–Ps assessment to determine high/ low level of need. Generally, two levels of need are being differentiated in each indicator which are Low (L) and High (H). For domains of anxiety and depressive symptoms, a "very high" (VH) level is also used. **Tables 4.4 — 4.8** summarise the need–stratifying indicators, thresholds of level of need, and the meaning of each level of need.

Table 4.4 Person at EoL： Indicators of physical needs

Assessment of Physical Symptoms reported by the Person at EoL					
Subdomains	Need stratifying Indicator	Scale scores	Remarks	Meaning & Thresholds for levels of need	
				Low (L) Need	High (H) Need
Physical Symptoms (13) (Palliative care outcome scale development team, 2017)#	Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has affected you over the past week：			**Low (L)：** **Except "Poor mobility", All item <3, and the sum of 13 item score >0** **Physical symptoms do not have severe impact on the P-Eoc**	**High (H)：** **At least one item other than "Poor mobility" scores ⩾3** **Physical symptoms have severe to overwhelming impact on the P-Eoc**
	Pain	0： Not at all (0%) 1： Slightly (30%) 2： Moderately(50%) 3： Severely (80%) 4： Overwhelmingly(100%)	Recommended descriptions on pain (Palliative care outcome scale development team, 2017)* 0： Not at all = No effect 1： Slightly = but not bothered to be rid of it 2： Moderately = pain limits some activity 3： Severely = activities or concentration markedly affected 4： Overwhelmingly = unable to think of anything else		
	Shortness of breath		Similar Chinese descriptions： 氣喘、不能呼吸		
	Weakness/lack of energy		Similar Chinese descriptions： 無精神、無氣力、成日好攰		
	Nausea		Similar Chinese descriptions： 作悶、噁心		
	Vomiting		/		
	Poor appetite		/		
	Constipation		/		
	Sore or dry mouth		rated according to the existing of either one condition or both		
	Drowsiness		Similar Chinese descriptions： 成日好想瞓、不能集中		
	Poor mobility		Similar Chinese descriptions： 活動能力欠佳 (這項目指整體活動能力)		
	Difficulty sleeping		/		
	Edema		/		
	Dizziness		/		
	Other symptoms		The person at EoL can specify other symptom(s) other than the above. If any symptom scores ⩾3, it is considered as high need		

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*This is recommended in the IPOS website (https://pos-pal.org/maix/how-to-score.php)

Table 4.5 Person at EoL: Indicators of psychosocial spiritual needs

Assessment of Psychosocial Spiritual Needs of Person at EoL					
Subdomains	Need stratifying Indicator	Scale scores	Remarks	Meaning & Thresholds for levels of need	
				Low (L) Need	High (H) Need
Anxiety (1 item) (Palliative care outcome scale development team, 2017)#	Over the past week, have you been feeling anxious or worried about your illness or treatment ?	4 = Always (100%) 3 = Most of the time (80%) 2 = Somtimes (50%) 1 = Occas (30%) 0 = Not at all (0%)	Worries over other disease-induced challenges should also be included. Expression of fear and dread (驚), irritability (易怒) should also be considered.	Low (L) = 1 **The P-EoL occasionally worried about his/her illness or treatment.**	High (H) = 2-3 Very High (VH) = 4 **The P-EoL sometimes to most of the time (2-3) or always (4) worried about his/her illness or treatment.**
Depressive Symptom (1 item) (Palliative care outcome scale development team, 2017)#	Over the past week, have you been feeling depressed?	4 = Always (100%) 3 = Most of the time (80%) 2 = Somtimes (50%) 1 = Occas (30%) 0 = Not at all (0%)	ICEST workers can elaborate the symptoms as low mood (低落), loss of interest (對所有事情失去興趣) and hopelessness (絕望). Non-verbal cues (e.g. lack of movement, flat affect, dejected demeanor etc.) and physical symptoms commonly associated with depression (e.g. appetite/weight change, changes in sleep pattern, loss of energy, fatigue, loss of libido, diminished concentration, etc.) (Rayner, Higginson, Price, & Hotopf, 2010, p. 13) should also be observed.	Low (L) = 1 **TheP-EoL occasionally felt depressed.**	High (H) = 2-3 Very High (VH) = 4 **The P-EoL sometimes to most of the time (2-3) or always (4) felt depressed.**

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Table 4.5 (continued) Person at EoL: Indicators of psychosocial spiritual needs

Assessment of Psychosocial Spiritual Needs of Person at EoL (Continued)					
Subdomains	Need stratifying Indicator	Scale scores	Remarks	Meaning & Thresholds for levels of need	
				Low (L) Need	High (H) Need
Spiritual Distress (7 items)	Over the past week…			**Low (L) :** All spiritual items score <3, but at least 1 item scores 2 **The P–EoL sometimes has spiritual distress, and/or sometimes feel good spiritually**	**High (H) :** At least one spiritual need item scores ⩾ 3 **The P–EoL most of the time to always has spiritual distress, and/or only occasionally or not at all feel good spiritually**
	Have you felt at peace? #	4 = Not at all (100%) 3 = Occasionally (80%) 2 = Somtime (50%) 1 = Most of the time (30%) 0 = Always (0%)	--		
	Have meaning in life?		Can also be expressed as having something to look forward in life (生活寄託), having something that you want to accomplish in life(有想做的事), having someone important to you in life (重要的人)		
	Have felt satisfied with life?		Can also be expressed as happiness(幸福), fulfilled(心滿意足), no regrets(無遺憾)		
	Have felt hopeful in life?		Can also be expressed as feel positive towards future (對未來正面), see the positive side of life (人生還有好的一面)		
	Have felt yourself a burden to family?	The reverse of above scoring	--		
	Have some unfinished businesses that you wanted to do (e.g. felt no chance to fix some unresolved problems, something left to be done, something that you want to do for your family etc.)		Can also be expressed as unfinished businesses/unresolved issues (未解的心結、有想做的事未做), something one wants to do for family(有想為家人做的事)		
	Have worried about afterlife?		--		

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Table 4.5 (continued) Person at EoL: Indicators of psychosocial spiritual needs

Assessment of Psychosocial Spiritual Needs of Person at EoL (Continued)				
Subdomains	Need stratifying Indicator	Remarks	Meaning & Thresholds for levels of need	
			Low (L) Need	High (H) Need
Social Distress (3 items)	Over the past week, how often did you have the following thoughts/feelings?		**Low (L) :** All social support items score <3, but at least 1 item scores 2 **TheP–EoL sometimes felt inadequate social support**	**High (H) :** At least one social support item scor ⩾ 3 **The P–EoL most of the time to always felt inadequate social support**
	Want to be with someone	4 = Always (100%) 3 = Most of the time (80%) 2 = Somtimes (50%) 1 = Occas (30%) 0 = Not at all (0%)		
	Felt lonely			
	You have many people to rely on	The reverse of above scoring		
Family Relationship△ (3 items) (Fok, Allen, Henry, & People Awakening Team, 2014 ; Moos & Moos, 1974)	Over the past week, how was your family relationships (including yourself)?		--	**High (H) :** Average score of the three family relation items ⩾ 2 **Family relational problem sometimes/ most of the time/always happen**
	Mutual support and care between family members	4 = Not at all (0%) 3 = Occasionally (30%) 2 = Somtime (50%) 1 = Most of the time (80%) 0 = Always (100%)		
	Family members openly express their thoughts and feelings to each other, including worries and discontentment, and even sensitive topics in the family			
	Conflicts between family members, and family members condemned and criticised each other	The reverse of above scoring		

△ Items on family relation were derived from the three subscales (cohesion, expressiveness, and conflict) in the Family Relationships Index (FRI) (Fok, Allen, Henry, & People Awakening Team, 2014), with one item representing one subscale from FRI Chinese version assessment tools are used in ICEST assessments.

Table 4.5 (continued) Person at EoL: Indicators of psychosocial spiritual needs

Assessment of Psychosocial Spiritual Needs of Person at EoL (Continued)				
Subdomains	Need stratifying Indicator	Remarks	Meaning & Thresholds for levels of need	
			Low (L) Need	High (H) Need
EoLC Decision Making [Preparatory ACP] **(4 items)**	1. Have you ever considered about the future medical treatment or care when your health condition deteriorates or when the disease has reached its terminal stage? ?	2 = No (Skip to Q4) 0 = Yes	**Low (L) :** Average score of all person at EoL decision making items ⩾ 1 but < 2 **The P–EoL has discussed EoL care plan with others already, but further discussion might be needed;** **OR** **P–EoL has not discussed EoL care plan with others yet, but expressed no need for discussion**	**High (H) :** Average score of all person at EoL decision making items ⩾ 2 **The P–EoL has discussed EoL care plan with others already, but further discussion is strongly needed;** **OR** **P–EoL has not discussed EoL care plan with others yet, and also expressed strong needs for discussion**
	2. Have you ever discussed these concerns with others?	4 = Nobody (Skip to Q4) 3 = Discussed with healthcare team that do not in–charge of your care 2 = Discussed with healthcare team that take care of you (but have not discussed with family members) 1 = Discussed with family member(s) (but have not discussed with healthcare team that take care of you) 0 = Discussed with family member(s) and healthcare team take care of you (or have no family caregiver, but have already discussed related concerns with healthcare team that take care of you)		
	3. Following the last question, how you felt after discussing with others on your future care?	4 = Much more worried or uneasy 3 = A little bit worried or uneasy 2 = No change/about the same as befo 1 = somehow at ease 0 = much more at ease		
	4. Do you think that your treatment and care plan at the late stage of your disease have been sufficiently discussed ?	4 = Not at all (0%) 3 = Quite insufficient (30%) 2 = half / half (50%) 1 = Quite sufficient (80%) 0 = Very sufficient (100%)		

Chinese version assessment tools are used in ICEST assessments.

Table 4.6 Person at EoL: Indicators of practical needs

Assessment of Practical Needs of Person at EoL				
Subdomains	Need stratifying Indicator	Scale scores	Meaning & Thresholds for levels of need	
			Low (L) Need	High (H) Need
Practical Problems (1 item) (Palliative care outcome scale development team, 2017)#	Over the past week, have any practical problems resulting from your illness been addressed? (such as financial or personal)	4 = Problems not addressed (0%) 3 = Problems hardly addressed (30%) 2 = Problems partly addressed (50%) 1 = Problems mostly addressed (80%) 0 = Problems addressed/No problem (100%)	Low (L) = 1 **Practical problems of P–EoL have been mostly addressed**	High (H) = 2–4 **Practical problems of P–EoL have been partly/ hardly/not addressed**
Information Needs (1 item) (Palliative care outcome scale development team, 2017)#	Over the past week, have you had as much information as you wanted?	4 = Not at all (0%) 3 = Occasionally (30%) 2 = Sometimes (50%) 1 = Most of the time (80%) 0 = Always/No such need (100%)	Low (L) = 1 **P–EoL has as much information as he/she wanted for most of the time**	High (H) = 2–4 **P–EoL sometimes/ occasionally/ not at all has as much information as he/she wanted**

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Table 4.7 Community carers: Indicators of psychosocial spiritual needs

Community Carers' Psychosocial Spiritual Needs				
Subdomains	Need stratifying Indicator	Scale scores	Meaning & Thresholds for levels of need	
			Low (L) Need	High (H) Need
Anxiety (1 item) (Palliative care outcome scale development team, 2017)#	Over the past week, have you been anxious or worried about your sick family member?	4 = Always (100%) 3 = Most of the time (80%) 2 = Somtimes (50%) 1 = Occasionally (30%) 0 = Not at all (0%)	**Low (L)** = 1 **CC occasionally worried about patient in the preceding week**	**High (H)** = 2–3 **Very High (VH)** = 4 **CC sometimes/ most of the time/ always worried about patient in the preceding week**
Depressive Symptoms (2 items) (Kroenke, Spitzer, & Williams, 2003)★	**Over the last 2 weeks, how often have you been bothered by any of the following problems?**		**Low (L) :** Sum of two depression item = 2 **CC had depressive symptoms for several days in the past two weeks**	**High (H) :** Sum = 3 **Very High (VH) :** Sum = 4–6 **CC had depressive symptoms for more than half the days in the past two weeks**
	Little interest or pleasure in doing things	3 = Nearly everyday (80%) 2 = More than half the days (50%) 1 = Several days (30%) 0 = Not at all (0%)		
	Feeling down, depressed, or hopeless			

★ Carer's depression was assessed with the Patient Health Questionnaire-2 (PHQ-2) which is a brief screening tool on depression applicable on general population. The scale was developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc. No permission required to reproduce, translate, display or distribute.
Some of these questions were retrieved from the Integrated Palliative Care Outcome Scale (IPOS) developed by the King's College London. Permission has been granted by the IPOS development team to translate the scale and reprint it in this manual. For using Chinese IPOS, please register and request a formal copy of the measure at www.pos-pal.org free of charge. Please do not make copy of the questionnaire in this manual.
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Table 4.7 (continued) Community carers: Indicators of psychosocial spiritual needs

Assessment of Psychosocial Spiritual Needs of Person at EoL (Continued)				
Subdomains	Need stratifying Indicator	Remarks	Meaning & Thresholds for levels of need	
			Low (L) Need	High (H) Need
EoLC Decision Making [Preparatory ACP] **(2 items)**	Have you ever discussed with the sick family member about his/her wish or preferences on treatment and care if his/her illness deteriorates or reaches the terminal stage?	4 = No, I am still contemplating/I am not prepared to talk to the sick family member about his/her preferences (for patient who has mental capacity and communication ability) 2 = No, but I am ready to ask the sick family member about his/her preferences (for patient who has mental capacity and communication ability) 0 = Yes, I have asked the sick family member about his/her preferences once or multiple times (for patient who has mental capacity and communication ability) N/A = The sick family member has no mental capacity to express his/her preferences	**Low (L) :** **All items in Carer EoL decision making <2, but at least one item =1** **CC has discussed EoL care plan with P–EoL, and had reached partial consensus**	**High (H) :** **Average score of all person at EoL decision making items making scores ⩾ 2** **CC has not discussed EoL care plan with P–EoL; or had discussion before but further discussion is needed or consensus not yet reached**
	Have you and your sick family member reached a consensus regarding treatment and care plan?	4 = Great disagreement (for patient who has mental capacity and communication ability) 3 = Slight disagreement (for patient who has mental capacity and communication ability) 2 = Inconclusive/not yet discussed (for patient who has mental capacity and communication ability) OR Uncertain (for patient who has no mental capacity to express his/her preferences) 1 = Consensus to a large extent (for patient who has mental capacity and communication ability) OR Quite understand and support sick family member's preference (for patient without mental capacity to express preferences, but carer anticipate patient's decision based on patient's personality and preference before losing his mental capacity) 0 = Consensus reached (for patient who has mental capacity and communication ability) OR Fully understand and support sick family member's preference (for patient without mental capacity to express preferences, but carer anticipate patient's decision based on patient's personality and preference before losing his mental capacity)		

Chinese version assessment tools are used in ICEST assessments.

Table 4.7 (continued) Community carers: Indicators of psychosocial spiritual needs

Community Carers' Psychosocial Spiritual Needs (Continued)				
Subdomains	**Need stratifying Indicator**	**Indication of higher risk**	**Meaning & Thresholds for levels of need**	
			Low (L) Need	**High (H) Need**
Risks of Grief ◊ (7 criteria) (Burke & Neimeyer, 2013 ; Lizabeth, James, & Latishia, 2016 ; Sophie, Henning, Jolande, Agnes, & Judith, 2015)	Below are seven risk factors of grief:		**Low (L) :** 1–3 risk(s) met **CC's pre–death risk for complicated grief is low**	**High (H) :** ⩾ 4 risks met **CC's pre–death risk for complicated grief is high**
	1. Relationship with person at EoL	Being spouse (of person at EoL)		
	2. Depressive symptoms	Carer depression assessment sum of score ⩾ 3		
	3. Anxiety	Carer anxiety assessment score ⩾ 3		
	4. Intimacy with the person at EoL Describe the level of intimacy of your relationship with your sick family member : *4=Very intimate 3=Quite intimate 2=Average 1=Quite distant 0=Very distant*	Intimacy with the person at EoL: Very intimate (4)		
	5. Dependency on person at EoL Overall, do you think that you are dependent on the sick family member (psychologically/daily life)? *4=Very dependent 3=Quite dependent 2=Average 1=Relatively not dependent 0=Not dependent at all*	Dependency on person at EoL: Quite dependent (3) OR Very dependent (4)		
	6. Familial support for caregiving Describe how sufficient the support you receive from your family members (other than the patient) in your role as a carer? *4=Totally insufficient 3=Relatively insufficient 2=Average 1=Quite sufficient 0=Very sufficient*	Familial support on caregiving: Relatively insufficient (3) OR Totally insufficient (4)		
	7. History of mental illness Please indicate whether you are diagnosed with any of the following chronic illnesses by a medical doctor:	History of mental illness: Psychiatric disease (e.g. depression)		

◊ According to an empirical review of risk factors associated with grief, authors suggested 6 salient risk factors of complicated grief including: (1) low social support, (2) anxious/avoidant/insecure attachment style, (3) discovering or identifying the body (in violent death), (4) being the spouse/parent of the deceased, (5) high pre-death marital dependence, and (6) high neuroticism. While not being the confirmed risk factors in the aforementioned study, affective disorder such as major depression, and the closeness with the deceased have been repeatedly found to be risk of grief. Therefore, compatible indicators from ICEST assessment were selected to indicate the risk of grief.
Chinese version assessment tools are used in ICEST assessments.

Table 4.7 (continued) Community carers: Indicators of psychosocial spiritual needs

Community Carers' Psychosocial Spiritual Needs				
Subdomains	Need stratifying Indicator	Scale scores	Meaning & Thresholds for levels of need	
			Low (L) Need	High (H) Need
Grief∀ **(19 items)** (Prigerson et al., 1995; Tang & Chow, 2017)	<u>Inventory of complicated grief (ICG) :</u> Please choose the most appropriate answer which best describes how you feel right now. The "person" in the sentences below refer to the deceased family member. 1. I think about this person so much that it's hard for me to do the things I normally do. 2. Memories of the person who died upset me. 3. I cannot accept the death of the person who died. 4. I feel myself longing for the person who died. 5. I feel drawn to places and things associated with the person who died. 6. I can't help feeling angry about his/her death 7. I feel disbelief over what happened. 8. I feel stunned or dazed over what happened. 9. Ever since s/he died it is hard for me to trust people. 10. Ever since s/he died I feel like I have lost the ability to care about other people or I feel distant from people I care about. 11. I have pain in the same area of my body or have some of the same symptoms as the person who died. 12. I go out of my way to avoid reminders of the person who died 13. I feel that life is empty without the person who died. 14. I hear the voice of the person who died speak to me. 15. I see the person who died stand before me. 16. I feel that it is unfair that I should live when this person died. 17. I feel bitter over this person's death. 18. I feel envious of others who have not lost someone close. 19. I feel lonely a great deal of the time ever since s/he died.	For each item : 4 = Always 3 = Often 2 = Sometimes 1 = RareIt 0 = Never Overall risk level of complicated grief is assessed by summing up the total scores of 19 items of inventory of complicated grief. This is to be assessed two months after loved one's death.	**Low (L) :** sum scores of 19 = 0–25 **CC's risk for complicated grief is low (After death of P–EoL)**	**High (H) :** Sum scores of 19 items = 26–76 **CC's risk for complicated grief is high (After death of P–EoL)**

∀ Complicated grief is assessed with the Inventory of complicated grief developed by Prof. Holly & Prigerson and translated by Prof. Amy Y.M.Chow. Permission has been granted by both parties to be displayed in this manual. Chinese version assessment tools are used in ICEST assessments.

Table 4.8 Community carers: Indicators of practical needs

Community Carers' Practical Needs				
Subdomains (number of items)	Need stratifying Indicator	Scale scores	Meaning & Thresholds for levels of need	
			Low (L) Need	High (H) Need
Caregiver Strain 8 **(13 items)** (W.C.H. Chan, Chan, & Suen, 2013 ; Thornton, & Travis, 2003)	<u>Example items of Caregiver Strain Index (13 items)</u> As caregiver, have you experienced any situation stated below : 1. Caregiving is a physical strain.(e.g. Moving furniture; Need to be focused) 2. My sleep is disturbed. (e.g. At night, the person I care wakes up due to insomnia and wander around) 3. There have been other demands on my time. (e.g. I also need to take care of other family members) 4. Caregiving is inconvenient (e.g. I need to spend lots of time or travel very far to help) 5. Caregiving is confining. (e.g. To help him/her, I have less leisure time or I can't go out) 6. There have been family adjustments. (e.g. Caregiving messes up my usual routine; privacy is lost) 7. There have been changes in personal plans (e.g. I need to reject jobs; I can't have vacation) 8. There have been work adjustments. (e.g. I have to take day-offs to provide care) 9. There have been emotional adjustments. (e.g. I need to handle disputes caused by the caregiving) 10. Some behavior is upsetting. (e.g. Incontinence; deteriorating of memory; being accused of taking away his/her belongings) 11. It is upsetting to find the person I care for has changed so much from his/her former self. (e.g. He/She becomes someone else, no longer who he/she used to be) 12. Caregiving is a financial strain. 13. I feel completely overwhelmed. (e.g. I am worried about the person I care; I always think about how the care should be provided)	For each item : 0 = No 1 = Yes, sometimes 2 = Yes, always Overall level of carer strain is assessed by summing up the total scores of 13 items of inventory of the modified caregivers strain index.	**Low (L) :** Sum of 13 items = 9–18 **CC had mild caregiver strain**	**High (H) :** Sum of 13 items = 19–26 **CC had high caregiver strain**
Information Needs (1 item)	Overall, do you think that others have provided you with sufficient information?	4 = Totally insufficient 3 = Insufficient 2 = Average 1 = Quite sufficient 0 = Very sufficient	**Low (L)** = 1 **CC has some information needs**	**High (H)** = 2–4 **CC has high information needs**

8 This is a 13-item modified caregivers strain index (m-CSI), developed by the Gerontological Society of American and translated by Prof Wallace Chan Chi Ho. Permission has been grant by both to be displayed in this manual. Chinese version assessment tools are used in ICEST assessments.

4.5 PRACTICAL TIPS WHEN ADMINISTERING THE ICEST 3P-NEED ASSESSMENT

Conducting an effective ICEST 3P–need assessment requires training and continuous practice. There are practical tips for facilitating the administration of ICEST 3P–need assessment (**Table 4.9**).

Practical Tips

Table 4.9 Practical tips when administering the ICEST 3P–need assessment

Recommendations	Elaboration
1. Engage the person at EoL and his/her carers	» Be prepared: read referral forms, and get in touch with referrers to obtain key information; » Visit when it is convenient for clients, e.g. when the person at EoL is most alert; » State purpose of assessment, time needed and areas to be covered; » Ask for permission rather than go directly into assessment; and » If carers are present, explore if the person at EoL wishes to be interviewed alone (or not).
2. Turn assessment into casual conversation	» Start with causal and relaxing topics; » Incorporate screening questions into casual conversation; » Never use the assessment tool as a checklist. Let the assessment conversation unfold in accordance with clients' preferences (led by person at EoL or by a community carer) and flexibly integrate the screening questions into the conversation; and » Leverage off the assessment to build relationships; and offer prompt interventions for pressing needs, if identified. Workers can provide reassurance, give information, provide advice or psychoeducation as appropriate.
3. Sequence assessment domains flexibly	» Adjust assessment coverage with consideration of clients' sense of urgency, readiness, capability and energy level; » For people with cognitive impairments, a proxy's information can be solicited for assessment (eg carers' or other relevant people's opinions can be solicited); and » When an identified need or problem is significant enough to warrant attention, ask additional questions to assess the underlying processes of the problem, explore previous coping strategies, strengths and resources which could help clients to confront the problem, examine the context in which the problem manifests, and the possibility of co–occurring life problems (such as financial worries).
4. Respect Individuality and Confidentiality:	» Respect the responses of the person at EoL in a non–judgmental manner, e.g. "level of pain", "meaning of life" are subjective perceptions and cannot be compared to others' responses; and » If the capacity of the person at EoL and the home environment allow, try to interview and assess the person at EoL and his/her carers separately in the first visit, so that everyone feels able to express their concerns frankly.

Table 4.9 (Continued) Practical tips when administering the ICEST 3P–need assessment

Recommendations	Elaboration
5. Use language that fits the cognitive and functional capabilities of the person at EoL:	» Use key words and simple language to ensure clear understanding; » Consider starting with binary (yes/no) questions, then followed by agreed percentages; and » Consider using visual aids, examples and prompts when needed.
6. Use good listening skills:	» Listen actively and empathetically, pay attention to non–verbal communications, including silence; » Pick up on important messages, values and beliefs from clients' narrative stories, and paraphrase these to achieve greater clarity in communication; and » Make good use of people's responses to screening items which may provide directions for interventions. For instance, items such as *"覺得還有些心願想要完成","把自己看成是家人的負擔","很想有人陪伴".*
7. Observe the environment:	» Observe home safety and hygiene, to screen for the need for comprehensive home safety assessment, community carer training, and /or other interventions to enhance function and safety; and » Observe the home environment, and relationships within the family, to understand more about clients' strengths, coping strategies, resources, and limitations. Information from the home environment may also tell ICEST workers about how family members interact with the person at EoL and how they go about their daily routines.
8. Wrap up the assessment with positivity and engagement:	» Acknowledge and validate clients' feelings and thoughts as understandable reactions, and recognise their efforts to cope with their current perceived difficulties, as appropriate; » Emphasise that there is more to the person at EoL than the disease; » Offer prompt advice as appropriate, such as psychoeducation on practical caring tips, information on community resources; and » Engage the person at EoL, and his/her community carers, in shared decision making in the care plan, which is likely to be the goal of next visit.
9. Empower clients in the process:	» Every person at EoL, and each one of his/her community carers, has life experiences that can provide important lessons for ICEST workers. It is important to let clients know that they are sharing with, and teaching ICEST workers, their life experiences. They are not just receiving help from the ICEST worker. This point should be emphasised because some clients may not be comfortable with seeking help, and may not understand the mutuality of the ICEST worker–client relationship.

Table 4.9 (Continued). Practical tips when administering the ICEST 3P–need assessment

Recommendations	Elaboration
10. Address spirituality:	» The domain of spiritual distress is perhaps the most difficult to assess; » Spirituality manifests differently for different people, such as religions, faith and personal beliefs, life meaning/ goals, inter–personal relations and even one's relationship with the universe (McCusker et al., 2020). It is also culturally sensitive; » As a rule of thumb, spiritual needs should be elicited in the later stage of the assessment after clients have become more comfortable with the assessment process. The discussion may follow their expressed worries on the impact of illness on faith, restrictions on culturally or religious practices, review on their life contributions or regrets, their desires or the goals they still want to achieve in their life. ICEST screening questions on spiritual distress can also be asked at that time, such as: *"您有否感到心境平和？", "覺得人生滿足", and "覺得還有些心願想要完成";* » Conversations about spiritual needs and life goals may lead on to EoL decision conversations such as ACP; and » Respect clients' unwillingness to discuss spiritual issues.

4.6 INFORMATION TECHNOLOGY-FACILITATED ASSESSMENT PROCESS

ICEST workers can obtain a full picture of clients' needs by completing the ICEST assessment on an online clinical data platform. The platform presents an assessment summary in real time (once the assessment was completed). Not only are ICEST workers able to immediately identify areas of high need, but they can also identify areas of low/no indicated needs that may suggest strengths and resilience. **Figure 4.1** outlines the real–time assessment summary for people at EoL and their community carers. Their levels of need are indicated with different colors and codes (**L**– Low, **H**– High, **VH**– Very High).

Results of person at EoL

		PT0	PT1	PT2
Evaluation Date		2019–03–28	2019–04–29	2019–07–02
Physical	Physical Symptoms	H	H	H
	Anxiety	L	L	L
	Depressive Symptoms	L	L	L
Psychosocial Spiritual	Spiritual Distress	H	H	L
	Family Relationships	H	NO	NO
	EoLC Decision making	H	H	NO
Practical	Practical Problems	H	L	L
	Information needs	H	L	H

Results of community at carers

		CG T0	CG T1	CG T2
Evaluation Date		2019–03–28	2019–07–02	
Psychosocial Spiritual	Depressive Symptoms	VH	L	/
	Anxiety	L	NO	/
	EoLC Decision making	H	H	/
	Pre–death Risks	L	L	/
	Post–death Grief	/	/	/
Practical	Caregiver Strain	H	NO	/
	Information needs	L	NO	/

VH	High (top) need
H	High (middle) need
L	Low
NO	No indicated

Figure 4.1 ICEST assessment results (example)

Importantly, the need–stratifying indicators can also serve as outcome measures. Changes in needs, and levels of need, at reassessment (e.g. 1st month and 3rd month for people at EoL, and 3rd month for community carers) can be used to evaluate the effectiveness of interventions (**Figure 4.2**).

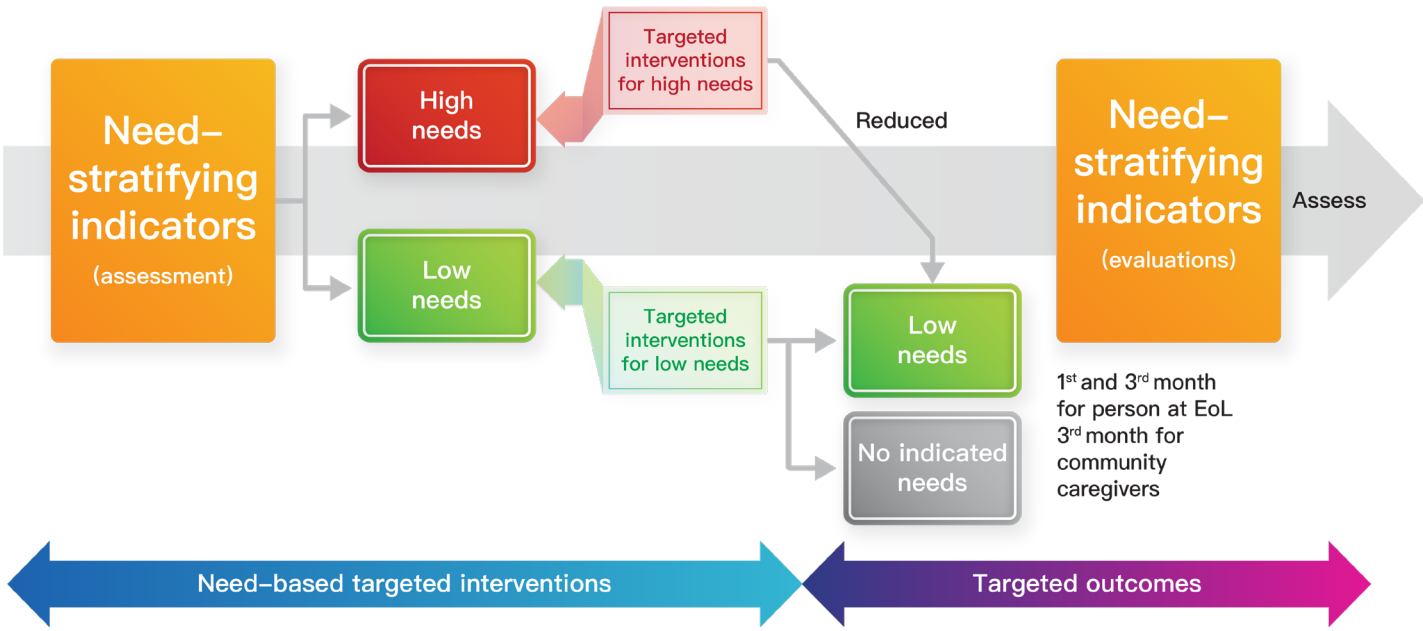

Figure 4.2 Facilitating achievements of targeted outcomes by using the need–stratifying indicators and stratified targeted interventions

More importantly, the ICEST model provides recommendations for targeted interventions for each level of need in all care domains. In general, for those domains showing no or low needs, only supportive care and regular monitoring is required. However, for those domains where there are high needs, ICEST workers should further explore underlying causes and circumstances with their clients. This is explained in more detail in the "PLAN" section in the next section, and the "INTERVENE" section in guidebook Volume TWO.

5. PLAN – PERSON-CENTRED CARE PLANNING

After clients have gone through the steps of Identify and Assessment, ICEST workers engage clients in discussing the results of the initial assessment, with the purpose of identifying preferences, prioritising care goals and agreeing to a shared plan with regular reviews. This section will offer guidelines on the third step – **Plan**.

5.1 ENGAGING CLIENTS IN THE PLANNING PROCESS

5.1.1 Identify Preferences

The ICEST worker liaises with clients to summarise and explain the needs identified from the assessment. Clients are then invited to rank their needs/concerns in order of importance to them.

Practical Tips

The ICEST worker should identify clients' readiness to change by asking the following questions:

- *What is important to you?*
- *What do you hope to do, and what prevents you?*
- *What do you want to change?*
- *How would you like your support to work?*
- *What would you like to do next?*

(Adapted from State of Victoria Department of Health, 2011)

Practical Tips

When preferences are not explicitly expressed

Sometimes the way preferences/ concerns are expressed is hidden in conversation, thus ICEST workers may need to clarify underlying messages to be sure that they understand what clients want. For example, a person at EoL may present his/ her wish to stay at home. When asked why this is important, he/ she may reveal the desire to be around the family (Family relation/social distress) or fear of being alone in hospital (Anxiety). This needs to be 'heard' by the ICEST worker, and further explored in a sensitive manner.

5.1.2 Prioritise Care Goals

Goal setting is vital in EoLC, for it allows transparent and timely negotiation of aims of care, empowers people at EoL and/or their community carers to make action plans, gives people at EoL a sense of purpose, and promotes greater satisfaction with the services that are offered (Bhatia, Reid, & Gibbins, 2014; Boa, Wyke, Duncan, & Haraldsdottir, 2012; State of Victoria Department of Health, 2011). Based on assessment findings and clients' preferences, care goals are set. However, when identifying realistic care goals and corresponding interventions, the ICEST worker also needs to facilitate the process of balancing clients' preferences with the cognitive and functional capabilities of the person at EoL within the context of their disease trajectory.

5.1.3 Agree to a Shared Plan with Regular Reviews

Mutual agreements with clients are crucial to achieving the intended outcomes.

Practical Tips

Considerations when selecting interventions

- The cognitive, functional, and communication capacities of people at EoL are crucial considerations when selecting interventions. For example, verbal counseling might not be as effective as exercise–based interventions for people who have serious hearing deficits and communication barriers.
- Similar considerations should be applied for those who have cognitive impairments. The attention span and energy level of people at EoL are all important factors to consider when planning how to provide necessary supports.
- Moreover, owing to limited life expectancies and unpredictable illness trajectories of some people at EoL, any session may be the last one. Hence, interventions, particularly those that target psychosocial–spiritual aspects, should be clearly focused, and goal oriented, so that the best outcome can be achieved quickly.
- When death is imminent, fatigue is common. The dying person may shift his/her concentration from the outer world to focus on the inner world. When that occurs, instead of active interventions, ICEST workers should provide only the supports that are deemed to be necessary by clients, and to be sensitive to the importance of private time for all concerned.

Interventions must be realistic and achievable in a reasonable timeframe. In addition to direct interventions to be provided by ICEST workers, clients' strengths, and resources should also be recognised and incorporated into the care plan. It is important to identify the readily–available sources of support for clients, such as other family members, friends, and community affiliations that clients might wish to access for themselves. This helps foster independence, promotes a sense of meaning for people at EoL, and enhances a sense of identity among clients.

The care plan needs to be reviewed regularly, particularly if any critical/ transitional moments arise, such as change of care place, hospitalisation or rapid exacerbations of illness. As a rule of thumb, the first three months after intake into the ICEST programme will be the most active phase of professional interventions, with primary goals of supporting carers to become comfortable with their new roles at home, and building psychological–spiritual resilience in the person at EoL and his/her carers to face the coming challenges. This is usually followed by a maintenance phase when the condition of the person at EoL stabilises. The frequency of professional intervention may reduce, and there may be increasing involvement of volunteers to engage in psychosocial activities and/or provide practical support. Another active phase may occur at critical/transitional points which are triggered by functional decline and/or increasing distress, such as acute illness exacerbations, hospital admission and discharge, changes in care settings, and start of treatments etc. Re–assessment followed by changed care plans to enhance coping and adaptation may be needed. Depending on the journey towards EoL, clients may cycle backwards and forwards between active and maintenance phases till the bereavement stage (**Figure 5.1**). It is important that at times of acute exacerbations, crisis interventions should be provided whenever possible. This could consist of emergency psychological support, timely practical help, and facilitation of communication between person at EoL, their community carer(s), and the healthcare team.

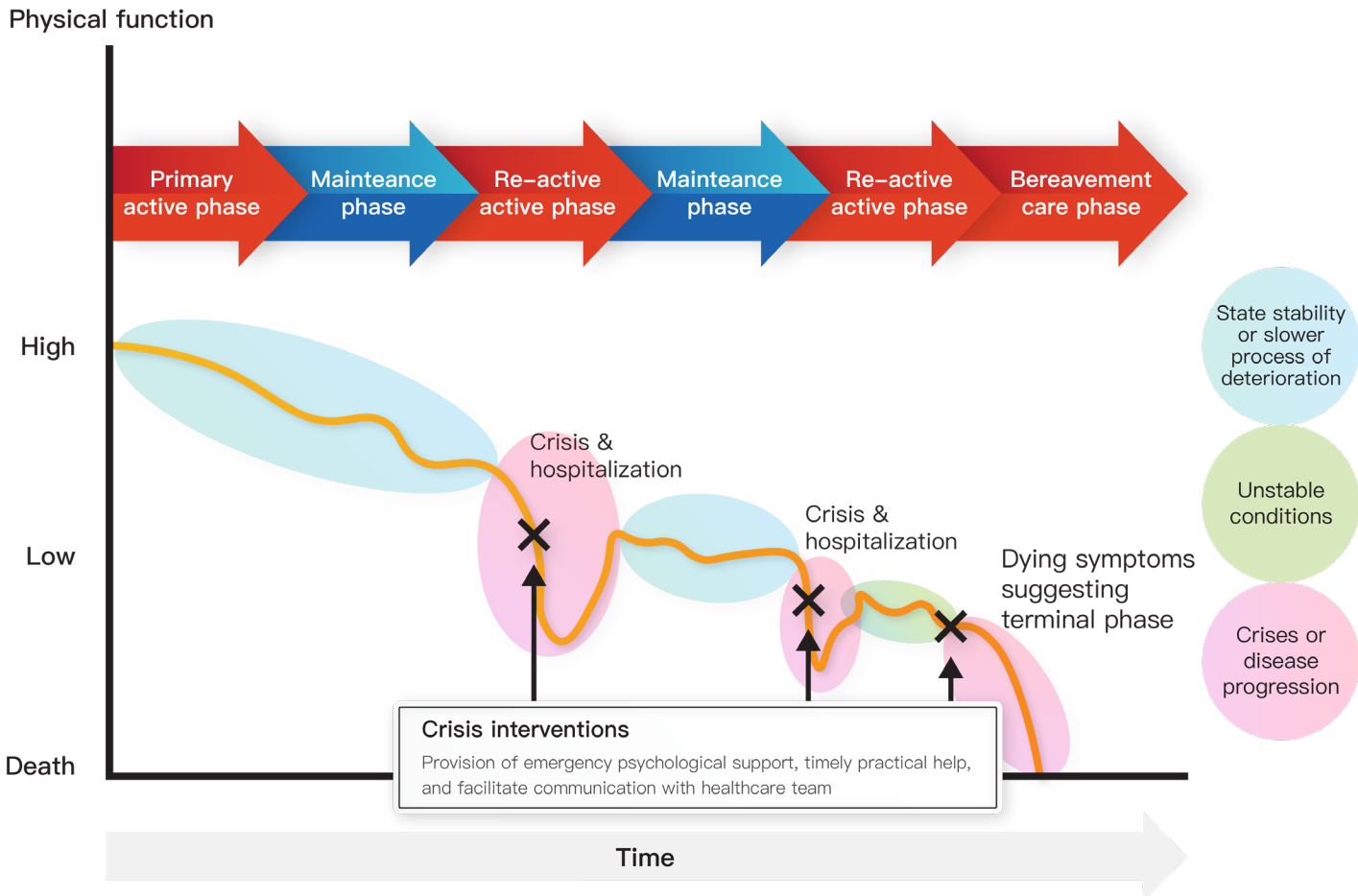

Figure 5.1 Alternation of active and maintenance phases until bereavement care phase is reached, using a typical disease trajectory of organ failure as an example

5.2 CASE CONCEPTUALISATION

After the standardised need–stratifying tool has been used for the initial assessment, levels of needs in each domain are differentiated as "Low" or "High". For anxiety and depressive symptoms, "Very High" level is added on top of "High" level. As a rule of thumb, if low needs are indicated, only general supportive care and continuous assessment to monitor changes is recommended. Should "high needs" be identified, in addition to general supportive care, further underlying causes of the problems, and specific interventions should be explored. The following guidelines may assist with the case conceptualization.

5.2.1 Further implicit assessment of areas of high need

Findings from the initial assessment provide a guide for ICEST workers to direct their attention to areas of high need, in order to explore appropriate interventions. ICEST workers may have to further explore the manifestations of presenting problems and underlying causes, including evaluating clients' strengths, resources, coping capabilities and preferences.

The questions in **Table 5.1** are suggested for more in–depth assessment of areas of high needs (adapted from the work of Dunn (2001) and the Holistic common assessment published by the National Health Services, UK (2010)). Some of this information should have been collected in the initial assessment interview (►**p.34** *Background information and assessment preferences*). How additional assessments lead to targeted interventions in each domain is outlined in the section "INTERVENE" of Volume Two.

Practical Tips

Table 5.1 Further assessment questions of areas of high need

1. Description of problems	» Onset/cause, duration, intensity, consistency, nature, and rate of changes and under what situations the changes happened (trigger).
2. Impacts of problems on clients' usual life activities and functioning	» How do they affect sleep, appetite, daily activities, relationships with others
3. Pre–existing problems and coping strategies that worked in the past	» Pre–existing medical, mental, and emotional problems, problem solving capabilities, habitual coping strategies and effectiveness.
4. Resources, challenges, and indent barriers	» Religions and beliefs, family relations and communication styles, social/ community support network, availability of accessible and reliable resources, physical limitations, education, and financial backgrounds; and » Client readiness to understand the illness and its trajectory; their willingness, and attitude, to accept/involve others in helping.

5.2.2 Comorbidity of 3P problems/needs

Dame Cicely Saunders suggested that people with life–threatening diseases may experience total pain, which is suffering that encompasses all the elements of a person's struggle (physical, psychological, social, spiritual, and practical) (Richmond, 2005). This reflects the philosophy of the biopsychosocial–spiritual model, where physical, psychological, social and spiritual dimensions are intertwined, and play key roles in an individual's overall wellbeing (Sulmasy, 2002). Considering people at EoL in the JCECC project in 2019, at least one–third presented with high needs in all three domains, while another third presented with co–morbid needs (defined as high needs in any two domains) (**Figure 5.2**).

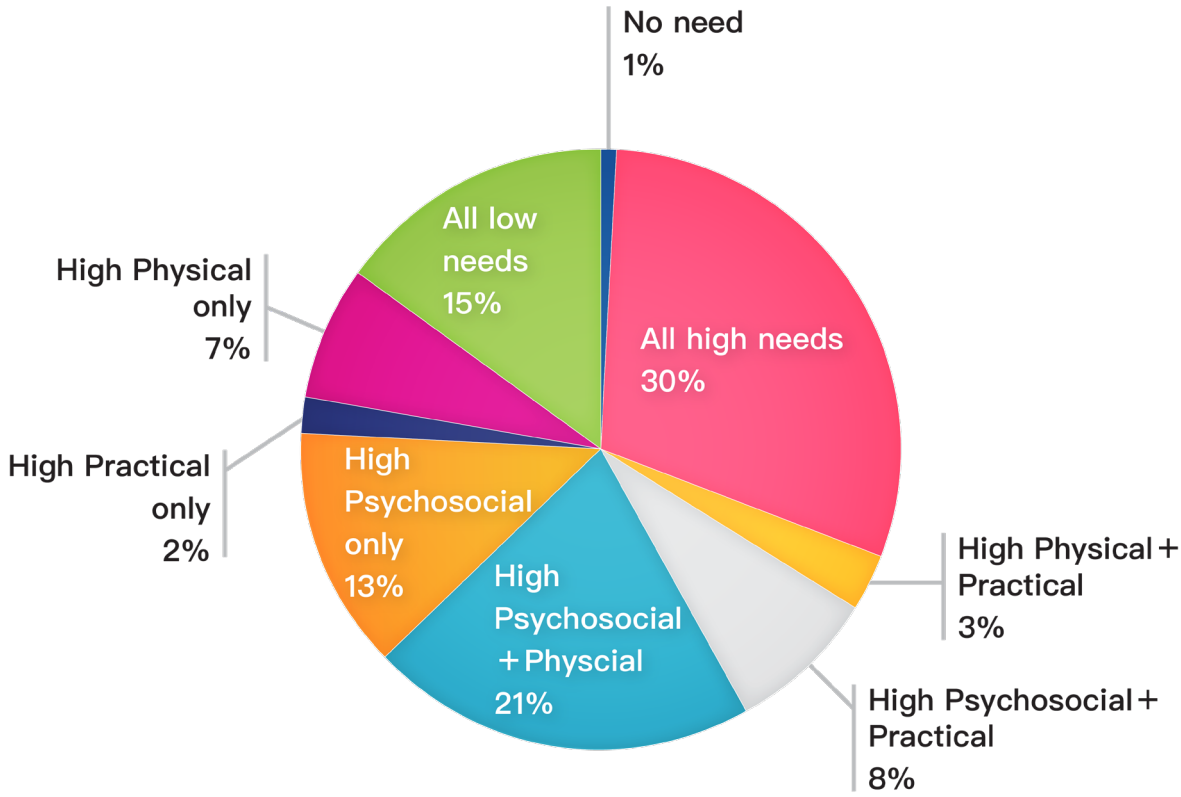

Figure 5.2 Comorbidity of the 3P needs of the person at EoL at baseline (N=315)

Most people at EoL suffer from comorbidities, which may be detected in key assessment domains (**Figure 5.3**). Thus, addressing physical and practical needs may assist in alleviating psychosocial problems. Apart from inter–dependence among domains, comorbid depression and anxiety are common in people at EoL and their carers (Areia, Fonseca, Major, & Relvas, 2019; O'Connor, White, Kristjanson, Cousins, & Wikes, 2010; Oliver, Washington, Smith, Uraizee, & Demiris, 2017; Wilson et al., 2007). Research suggests that spirituality is strongly associated with anxiety and depression, however spiritual distress can also be experienced without emotional distress (Hui et al., 2010; Rego et al., 2018).

Anxiety	» Poorly–controlled symptoms (physical) (Delgado–Guay, Parsons, Li, Palmer, & Bruera, 2009; Stoklosa, Patterson, Rosielle, & Arnold, 2011; Wilson et al., 2009); » Unmet healthcare information needs (practical) (Wang, Molassiotis, Chung, & Tan, 2018); » Depression (psychological) (Areia, Fonseca, Major, & Relvas, 2019; O'Connor, White, Kristjanson, Cousins, & Wikes, 2010; Oliver, Washington, Smith, Uraizee, & Demiris, 2017; Wilson et al., 2007); and » Death anxiety and piritual distress (spiritual) (Hui et al., 2010; Rego et al., 2018)
Depressive symptoms	» Pain (physical); » Functional limitations exacerbated by limited self–care and social activities (physical, practical and social) (Austin, Wiley, McEvoy, & Archer, 2011); » Family conflict (family) or loss of meaning in life (spiritual) (David Hui et al., 2010; Rego, Pereira, Rego, & Nunes, 2018); and » Anxiety (psychological) (Areia, Fonseca, Major, & Relvas, 2019; O'Connor, White, Kristjanson, Cousins, & Wikes, 2010; Oliver, Washington, Smith, Uraizee, & Demiris, 2017; Wilson et al., 2007)
Some physical symptoms (e.g. insomnia)	» Indicator of depression (psychosocial–spiritual)

Figure 5.3 Common comorbidities among psychological, practical, and physical distresses in people at EoL

Practical Tips

A general rule of thumb in dealing with multiple high needs in 3–Ps

According to Maslow's hierarchy of needs (Maslow, 1987), people's more basic needs (such as physiological and safety needs) should be fulfilled first before pursuing higher level needs (e.g. love and belonging, esteem, self–actualisation). Hence, in people with multiple high needs, practical and physical needs should be given higher priority and should be addressed in a timely manner, in order to minimise undue stress.

5.2.3 Conjoint or Individual Interventions

Anxiety & depressive symptoms of the person at EoL, and their community carers, is believed to be inter–dependent (Jacobs et al., 2017; Li, Lin, Xu, & Zhou, 2018; Oechsle, Goerth, Bokemeyer, & Mehnert, 2013). For instance, anxiety and depressive symptoms expressed by community carers can be jointly associated with the progression of their loved one's disease (Williams & Mccorkle, 2011), and poorly managed symptoms (Oechsle et al., 2019). Poor family functioning can predict clients' anxiety and depression, and other psychological morbidities such as distress, somatisation, and complicated anticipatory grief (Areia et al., 2019; Kissane & Bloch, 2002). Kissane (2016) estimated that approximately 1:4 (25%) families with a loved one with advanced cancer required specialised psychosocial interventions. At–risk families may be identified by assessing family functioning, for instance their cohesiveness, expressiveness and conflict resolution. Below are some practical tips in deciding whether conjoint or independent interventions should be used.

Practical Tips

Determining conjoint or independent interventions

Where high need domains are shared by both the person at EoL and community carers, ICEST workers may need to first identify inter–dependence or shared root problems. Consensus should be reached if the person at EoL and key community carers share the same perceived needs and are willing to work towards resolving them. Sometimes, shared needs should be dealt with individually, because of their complexity. Since carers' perceived needs may differ from those of the person at EoL, carers should be given time and opportunity to reflect on their individual needs, and to identify possible solutions.

5.3 Care delivery in ICEST stepped-care model

The stepped–care ICEST model coupled with care domains has implications for care delivery and resource allocation. According to the assessed level of client need in each care domain, interventions of differing intensities may be required. A high level of need may require intensive active interventions provided by the ICEST worker best qualified to do so (**Figure 5.4**). Physical care may be led by the team nurse, while social workers are generally responsible for psychosocial–spiritual care. Practical care is mainly delivered by supporting care workers under the supervision of a social worker.

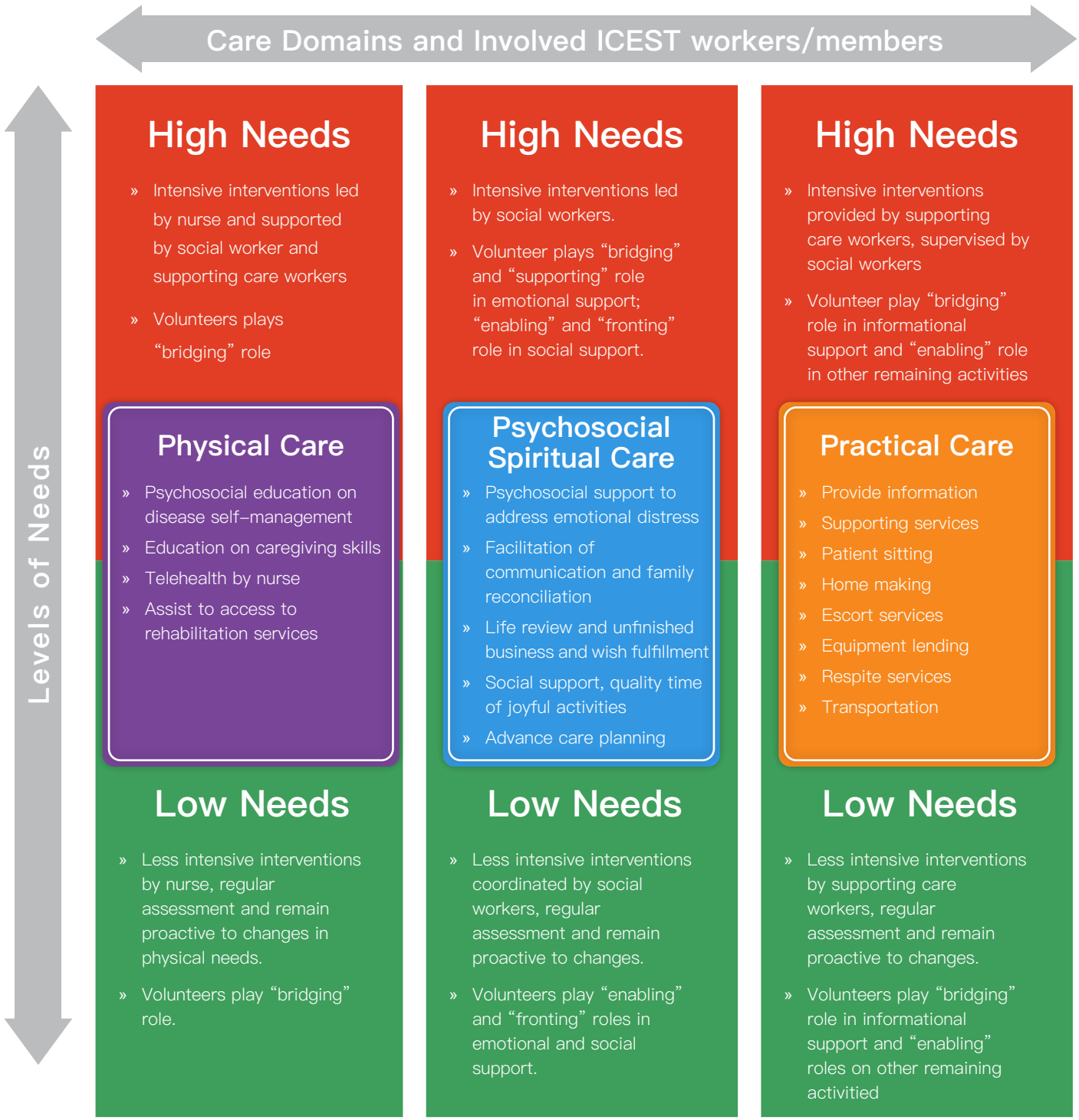

Figure 5.4 Different intensities of stepped care in each domain, in the ICEST model

Volunteers are strategically nurtured to contribute to the EoLC team via the SENS approach (Stimulating a shared value; Enabling a collective act; Nurturing an integrated team; and Sustaining a companionate community) (Please visit www.jcecc.hk and download the volunteer coordinator guidebook「安寧義工服務發展與統籌手冊」published in 2021 [Only Chinese available]).According to their EoL knowledge, experience and commitment, volunteers can play four key roles under the ICEST model: bridging role, supporting role, enabling role, and fronting role (**Figure 5.5**).

Figure 5.5 Roles of volunteers in the ICEST model

The Bridging and Supporting roles relate to indirect care provision and support, while the Enabling and Fronting roles refer to direct provision of care and support.

Please refer to guidebook Volume Two on implementation details of the fourth step — intervene. Guidebook Volume Two will be presented to participants who attend the ICEST training.

APPENDIX 1

Standardised Referral Form (Sample)

Referral form (P.1)

Referral Form for Jockey Club End-of-Life Community Care Project (JCECC)

☐ TO : St. James' Settlements (SJS)
(Phone / Fax : Phone / Fax numbers
Email : email address inserted)

FROM : Palliative Care / Oncology of ☐ PYNEH ☐ RTSKH
(Phone / Fax : _____ / _____
Email : _____)

☐ TO : HK Society for Rehabilitation (HKSR)
(Phone / Fax : Phone / Fax numbers
Email : email address inserted)

FROM : Medical / Geriatrics of ☐ PYNEH ☐ RTSKH
(Phone / Fax : _____ / _____
Email : _____)

Consent

1. Verbal consent of referral obtained from

☐ Patient and / or

☐ Family member : _____
on _____(date) for patient pareferral to SJS or HKSR under JCECC and release of the information as listed in the referral form to SJS or HKSR for JCECC enrolment

2. Diagnosis known to patient : ☐ Y ☐ N

3. Diagnosis known to family : ☐ Y ☐ N ☐ Not Sure

Patient's Personal Information

Name : _____(Chinese preferred)

Gender : _____ Age : _____ Contact No. : _____

Address : _____

Family Member Information

Name : _____ Relationship : _____

Contact No. : _____

Medical Background

4. Diagnoses :

5. PPS (%, if any) : _____

6. Current Infectious Disease : ☐ Y : _____ ☐ N

6. HARRPE score (0–1, if any) : _____

8. Mental Illnesses : ☐ Y : _____ ☐ N

9. ACP Discussed : ☐ Y ☐ N ☐ Not Sure
AD Signed : ☐ Y ☐ N ☐ Not Sure

Psychosocial Background

10. Psychosocial Spiritual Distress of Patient :
☐ Y : _____ ☐ N

11. Psychosocial Spiritual Distress of Family member :
☐ Y : _____ ☐ N

12. Suicidal Ideation of Patient :
☐ Y ☐ N ☐ Not Sure

13. Family Issues : ☐ Y : _____
☐ N ☐ Not Sure

Recommended Services

Physical Care	Psychosocial – Spiritual Care	Practical Care
☐ Personal care	☐ For patients	☐ Escort
☐ Education on physical care	☐ For family	☐ ADL/Household chores
☐ Equipment loan	☐ Preparatory ACP	☐ Social Services Navigation

☐ Receive periodic reviews, in addition to initial need assessment and service plan

☐ Other Remarks, if any :

_____

Referrer's Information

Contact Person Name/ Post
(if different from referrer) : _____ Contact Number : _____

Referrer's Name/Post : _____ Signature : _____ Date : _____

For Office Use Only Received on : _____ Case No : _____

Notes to Referrer

Referral form (P.2)

Eligibility Criteria

1. prognosis of less than 12 months;
2. indication of psycho–social or spiritual distress;
3. preferably aged 60 or above;
4. currently not covered under the existing Integrated Discharge Support Programme for Elderly Patients or similar services; and
5. referred by PYNEH or RTSKH.

Scope of EoLC Services (3–Ps)

1. Physical Care：	Personal care, Patient & family education on physical care, Equipment loan
2. Psychosocial–Spiritual Care：	Professional counselling for patients, Education on caring skills & stress management for family members, Facilitation of family communications / reconciliation, Befriending volunteer support for patients & family, Preparatory ACP, Bereavement & funeral support (upon death of patient)
3. Practical Care：	Escort, ADL / Household chores, Social services navigation

* SJS / HKSR will acknowledge receipt of case referral and phone contact patient / family member within 3 working days ; and arrange ward visit / home visit within 5 working days by social worker or nurse.

Suggested script to engage patient and/or family and introduce JCECC EoLC service.

1. 我哋好關心您同您家人出院後嘅情況，希望可以係醫院以外提供多一種支援，所以想轉介您哋俾(香港復康會 / 聖雅各福群會) 嘅賽馬會安寧頌計劃。
2. 呢個服務由香港賽馬會贊助，主要服務內容免費。(附上服務單張)
3. (香港復康會/ 聖雅各福群會) 會同我哋緊密合作，佢哋嘅社工或護士會同您哋傾下偈 、睇下有乜嘢可以幫到您們，譬如教屋企人點樣照顧病人，或者有義工陪下您們等等。
4. 我哋將您嘅地址、電話和簡單病歷等交俾(香港復康會 / 聖雅各福群會)，佢哋會打電話俾您/您家人，約嚟醫院或去您屋企探訪。好唔好呀？

APPENDIX 2

Initial Assessment and Service Plan (Sample)

Initial Assessment and Service Plan

☐ Palliative Care / Oncology of ☐ PYNEH ☐ RTSKH
(Phone / Email : _____ / _____)

FROM : St James' Settlements
(Phone / Fax : *Phone and Email inserted*)

☐ Medical/ Geriatrics of ☐ PYNEH ☐ RTSKH
(Phone / Email : _____ / _____)

FROM : HK Society for Rehabilitation
(Phone / Fax : *Phone and Email inserted*)

Name of Patient : _____ Case Number : _____

Care Area	Need Level	Service Content			
Physical :	☐ Hi ☐ Lo	☐ Personal Care	☐ Patient / family education on physical care	☐ Equipment Loan	☐ Others : _____ _____ _____
Psychosocial Spiritual :	☐ Hi ☐ Lo	☐ Professional counselling for patients	☐ Education on caring skills & stress management for family members	☐ Facilitation of family communication / reconciliation	☐ Befriending volunteer support for patients and family
		☐ Preparatory ACP	☐ Others : _____		
Practical :	☐ Hi ☐ Lo	☐ Escort	☐ ADL / Household chores	☐ Social services navigation	☐ Others : _____ _____ _____

Service Referral : ☐ Y : _____ ☐ N

Other remarks :

_____

_____

_____

Prepared by :

Name / Post : _____ **Contact Number :** _____

Signature : _____ **Date :** _____

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GLOSSARY OF TERMS

3

3–Ps	Care domains in ICEST: Physical care/needs, Practical care/needs, Psychosocial spiritual care/needs.

A

A	Abbreviation of "Assessment": Refer to one of the recommended actions in the ICEST intervention recommendations.
ACP	Advance Care Planning
AD	Advance Directives
ADL	Activities of Daily Living
APA	American Psychological Association

C

CBT	Cognitive Behavioural Therapy
CC	Community carers: In this manual, community carers refer to unpaid and informal carers living in the community who provide care to a loved one who is facing EoL. They can be family (spouse, children, siblings), friends and/or neighbours of the person at EoL.
CCSV	Community Care Service Voucher
CC–T0	Abbreviation of "Assessment": Refer to one of the recommended actions in the ICEST intervention recommendations.
CC–T1	Questionnaire code for community carer second assessment
CC–T2	Questionnaire code for community carer grief assessment
CNS	Community Nursing Service
COVID–19	Coronavirus disease 2019
CSNAT	Carer Support Needs Assessment Tool
CUHK	The Chinese University of Hong Kong

D

DECC	District Elderly Community Centres
DE	Day Care Centres for the Elderly

E

EHCCS	Enhanced Home and Community Care Services
EoL/EOL	End of Life
EoLC	End of Life Care
EoLCC	End of Life Community Care
ESMO	European Society for Medical Oncology

F

FHB	Food and Health Bureau
FICA	A spiritual screen tool with the following four aspects: F– Faith and Belief, I– Importance, C–Community, and A–Address in Care
FRI	Family relation index: Used to develop the assessment indicator on "Family relationships".

G

GAD–7	General Anxiety Disorder–7: A screening tool on general anxiety disorder
General supportive care	General supportive care: care that is provided to support those with low level of needs in ICEST.
GSF PIG	Gold Standards Framework Proactive Identification Guidance

H

H	Indicates high level of needs in 3–Ps domain.
HARRPE	Hospital Admission Risk Reduction Programme for the Elderly: An assessment tool on re–admission risk. Being used in the referral form of ICEST.
HCSPSD	Home Care Service for Persons with Severe Disabilities
HK	Hong Kong
HKHA	Hong Kong Hospital Authority
HKSAR	Hong Kong Special Administrative Region
HKU	The University of Hong Kong
HSE	Health Service Executive (Ireland)

I

I	Abbreviation of "Intervene": Refer to one of the recommended actions in the ICEST intervention recommendations.
IADL	Instrumental Activities of Daily Living
ICEST	Integrated Community End–of–life Care Support Team: A unified and standardised community–based end–of–life care model developed under the JCECC.
ICEST clients	People at EoL and their community carers who are cared for by ICEST.
ICG	Inventory of complicated grief: Used to assess the grief reactions of bereaved carers in ICEST.
IDSP	Integrated Discharge Support Program for Elderly Patients
IFSC	Integrated Family Services Centres
IHCS	Integrated Home Care Services for frail cases
IOM	Institute of Medicine
IPOS	Integrated Palliative Care Outcome Scale: A scale developed by the King's College London to measure the outcome of palliative care. Translated and used in ICEST to assess person at EoL.

J

JCECC	Jockey Club End–of–Life Community Care (Project)

L

L	Indicates low level of needs in 3–Ps domain
LWB	Labour and Welfare Bureau

M

MBCT	Mindfulness–based Cognitive Therapy
MBSR	Mindfulness–based Stress Reduction (Training)
m–CSI	Modified Caregiver Strain Index: Used to assess the caregiving strain of community carers in ICEST.
MSS	Medical social services

N

N	Nurses in ICEST.
NGO	Non-Government Organisation
NHS	National Health Services (UK)
NICE	National Institute for Health and Care Excellence (UK)
NURSE	An empathetic communication framework: Naming, Understanding, Respecting, Supporting, and Exploring.

P

P-EoL	Person/People at EoL: The term 'person/people' is used in preference to patient, to emphasise the holistic person-centered nature of the ICEST approach.
PCQ	Phase change questionnaire: An assessment questionnaire that is used in ICEST when there is a critical change/transition in care.
PE-T0	Questionnaire code for P-EoL first assessment
PE-T1	Questionnaire code for P-EoL second assessment
PE-T2	Questionnaire code for P-EoL third assessment
PHQ-2	Patient Health Questionnaire-2: Used in ICEST to detect depressive symptoms of community carers.
PHQ-9	Patient Health Questionnaire-9: A depressive symptom screening tool.
PMR	Progressive muscle relaxation
PPE	Personal protective equipment
PPS	Palliative Performance Scale: Used in the referral form of ICEST to assess person at EoL's functional performance.
PST	roblem-solving therapy, the steps ("ADAPT") of which are: "A" adopt a positive problem-solving attitude; "D" define the problem and set realistic goals; "A" generate alternatives and make use of the strengths & resilience of the person at EoL; "P" predict the consequences and develop solution plans; and "T" try out the plan as a possible solution.

R

R	Abbreviation of "Refer": Refer to one of the recommended actions in the ICEST intervention recommendations.
RCTs	Randomised control trials

S

SCW	Supporting care worker in ICEST, usually works under direction of social workers.
SENS approach	Abbreviation of an approach adopted to train volunteers in ICEST: Stimulating a shared value; Enabling a collective act; Nurturing an integrated team; and Sustaining a companionate community.
SICG	Serious Illness Conversation Guide
SKH/S.K.H.	Hong Kong Sheng Kung Hui
Specific intervention	Specific intervention: care that is provided to support those with high level of needs in ICEST.
SPIKES	Abbreviation of a 6-step protocol on breaking bad news : Setting, Perception, Invitation, Knowledge, Empathy, and Summary.

SROI	Social Return on Investments
Stepped–Care Model	Stepped–Care Model: A care delivery model adopted in ICEST to guide the delivery of care based on level and type of needs identified.
SWD	Social Welfare Department
SW	Social Worker in ICEST.

T

Threshold values	hreshold values: A value embedded in the 3–Ps assessment indicator for indicating different levels of needs.

V

V	Volunteers in ICEST.
VH	Indicates very high level of needs in 3–Ps domain.