



Evaluation of a Manualized Need-based Community End-of-Life Care Service Model

JCECC International Conference 2021 June 18

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策劃及捐助 Initiated and funded by:



香港賽馬會慈善信託基金
The Hong Kong Jockey Club Charities Trust
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合作夥伴 Project Partner:



The need for a need-based EoLC

There is **NO** 'one size fits all' approach in EoLC

- Patients with life-limiting disease and their caregivers may have a range of unmet physical, emotional, social and spiritual needs
- Patients have various journeys depending on the severity of their conditions and their health needs

(Hanan & Eli, 2018)

The need for a need-based EoLC

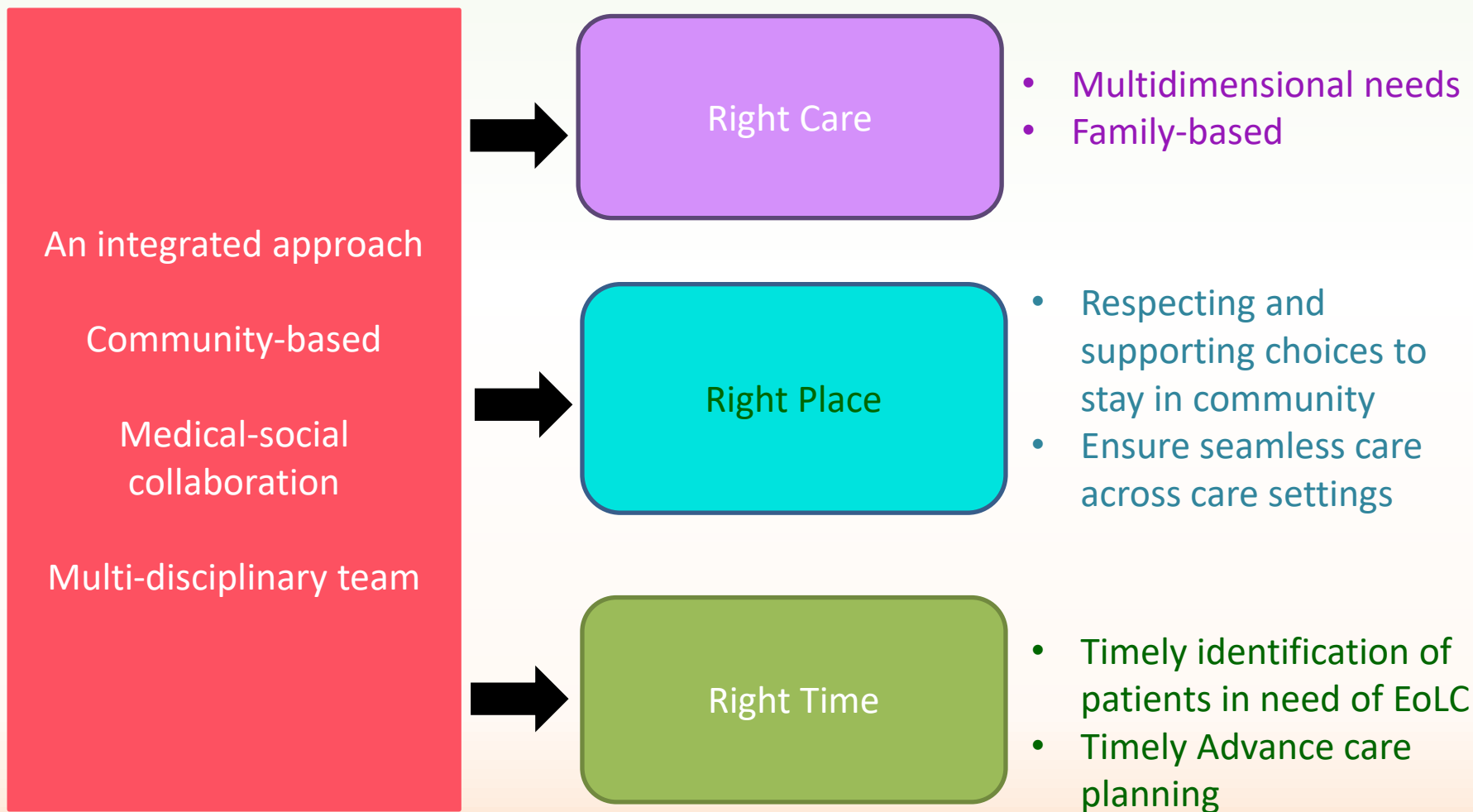


People at the end of life need to get the right care, in the right place, at the right time. This is the focus of much recent evidence. We have organised key findings from the most relevant recent NIHR funded research into the following sections:

- Right care
 - Caring by general staff
 - Accessing specialist palliative care
 - Dementia and the very old
- Right place
 - Choosing where you live and die
 - Joining up the care
- Right time
 - Getting care in time
 - Making the right decisions

(National Institute for Health Research, 2015, P.7)

Important Elements in Need-Based EoLC



The JCECC Project

In 2016, the JC Trust approved 255 million to launch the 6-year Jockey Club End-of-Life Community Care Project (“JCECC”), aimed at **improving the quality of end-of-life (EoL) care, enhancing the capacity of service providers**, as well as **raising public awareness**. It is a multi-disciplinary, multi-institutional and cross-sectoral collaboration, with special emphasis on the interface between social and health care systems.

Stakeholders and System

Project Components

Project Objectives



Hospital
醫療機構



RCHEs
安老院舍



Home and
Community
家庭及社區



The General Public
公眾人士

Capacity Building Programmes at Hospital
醫療機構人員能力提升項目



District-based Support for RCHEs
安老院舍地區支援



Community-based
Innovative Services by NGOs
社福機構創新服務



Knowledge and Skill Transfer
知識與技術轉移



Professional
Capacity Building
專業能力培訓

Impact Assessment
and
Programme Evaluation
成果效益評估



Enable Alternative
Choice of Care



Extend Services to
Wider Patient Population



Strengthen Medical-
Social Collaboration



Enhance End-of-Life
Care Competence



Assess Project Impact
and Cost Implication

Four Pilot Community EoLC Models (2016 – 2018)



NGOs

Enhanced
community health
care model

Family capacity
building model

Non-cancer patient
capacity building
model

Community capacity
building model

Patients

Cancer & non-
cancer

Cancer & non-
cancer

Non-cancer

Cancer & non-cancer

**Community
Partners**

Medical
Professionals

Community
elderly support
team + Family

Patient Groups +
Professional
Volunteers

Church Groups

Focus





Community
enhanced
medical
support model

Family-based
approach

Non-cancer
patient
focused

Community
building
approach

Effective Interventions in Pilot Programmes (2016-2018)

	Symptom management	Psychosocial care	Practical support	Communication	EoL Decision Making	Bereavement Care
Common intervention components		<ul style="list-style-type: none"> Counseling Emotional support Legacy Wish fulfilment 	<ul style="list-style-type: none"> Equipment loan/consultation Escort Service referral 	Facilitate family communication	Care preference discussions	Bereavement support
	<ul style="list-style-type: none"> Health consultation Alternative therapies 	Mutual support group/visits Volunteer support		Family reconciliation	Funeral planning	Funeral support
	Symptom self management education	<ul style="list-style-type: none"> Joyful activities Positive death education 				
	<ul style="list-style-type: none"> Home-based nursing care Telemedicine 	Spiritual care		ACP discussion	ACP review	
 St. James' Settlement	Occupational therapy	Cheer-up activities	Caregiver stress relief sessions	Cheer-up activities	Funeral planning	Funeral support ⁷

Development of the Integrated Community

End-of-Life Care Support Team (ICEST)

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Jockey Club End-of-Life Community Care Project

Conduct systematic literature review to develop evidence-based assessment & intervention guide for the ICEST

Systematic literature review

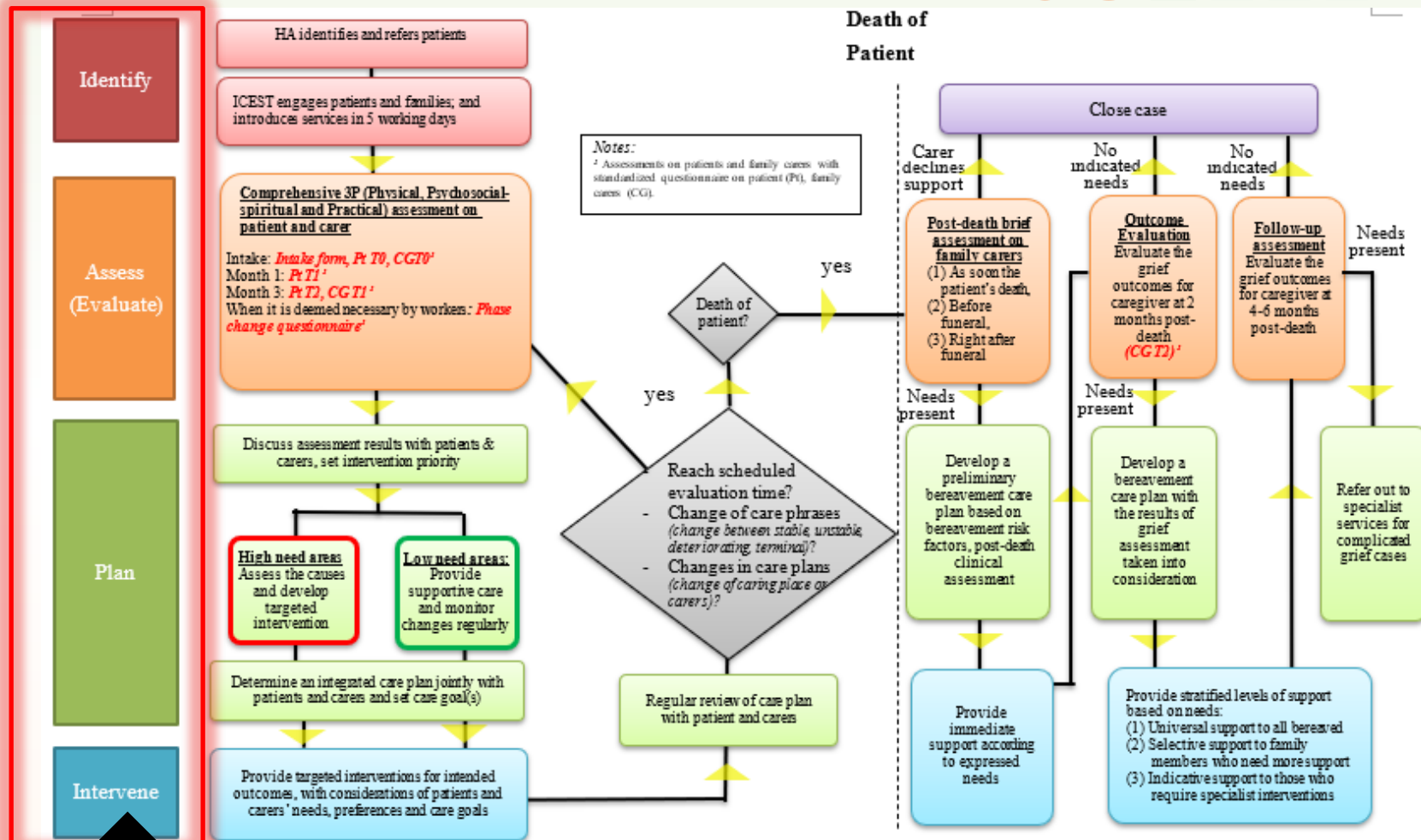
Participation of stakeholders

Consultations with representatives of Food and Health Bureau, Labour and Welfare Bureau, Hospital Authority, and Social Welfare Department
Model building workshops with NGO partners

Evidence from service evaluations

Synthesis of findings and implications from mixed method research in evaluation of pilot community based EoLC service models between 2016- 2018

ICEST Feature 1: Standardised Care pathway



- 4-step care pathway adapted from the central processes of Gold Standard Framework (The Gold Standards Framework, 2016)
- Close collaboration with hospital

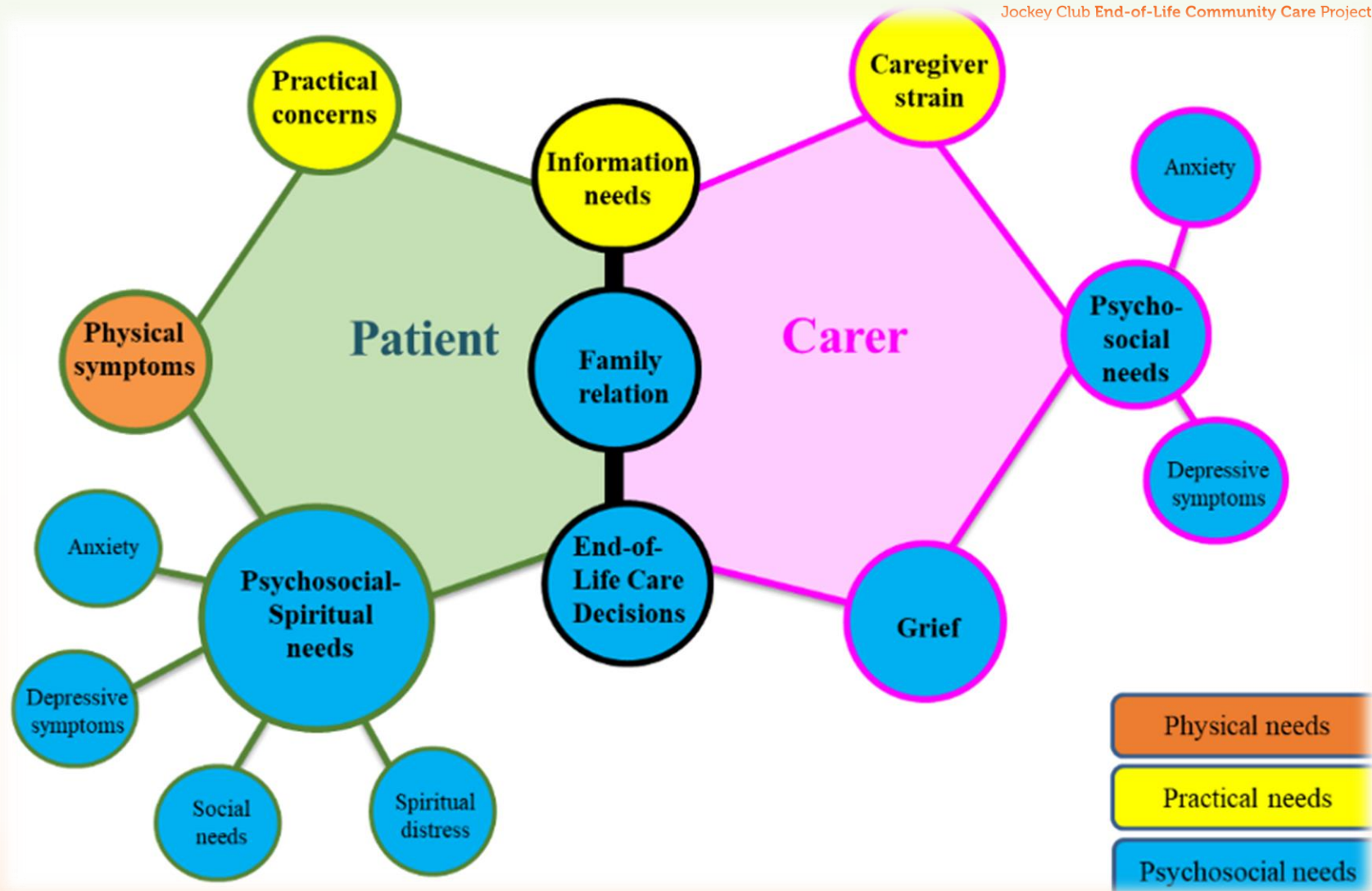
ICEST Feature 2:

Standardised & Holistic Assessment (1)

- **Needs assessment:** Multi-dimensional assessments on patients and caregivers' needs
- **Clinical: 3-Ps (physical, psychosocial spiritual, practical) assessment** composed of risk-stratifying indicators for care planning
- **Outcome evaluation:** repeated assessments to evaluate outcomes



ICEST Feature 2: Standardised & Holistic Assessment (2)

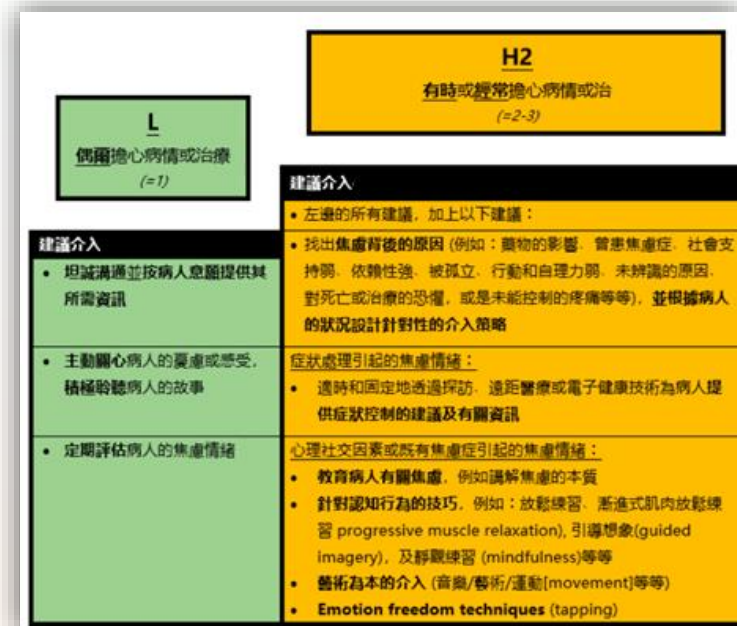


ICEST Feature 3: Need-based Care planning

- Need-based care planning facilitated by holistic assessment and real-time assessment results supported by technology



	第一次評估		第二次評估		建議介入
	PT0	Staff T0	PT1	Staff T1	
		2019-07-18	2019-08-06		
患者身體症狀		H	H		建議介入
患者焦慮情緒		H2	NO		建議介入
患者抑鬱情緒		H2	NO		建議介入
患者心靈支援		/	H	/	建議介入
患者社交需要		/	L	/	建議介入



Assessment
Platform

Real-time
Assessment

Target Intervention
Recommendations

ICEST Feature 4: Manualised targeted evidence-based interventions (1)

Development of Intervention Recommendations

- Literature search on evidence-based clinical practice in palliative and EoLC (search up to 2000) according to the search strategy in Clinical Decision Support Tool developed for the IPOS items

van Vliet et al. *BMC Medicine* (2015) 13:263
DOI 10.1186/s12916-015-0449-6



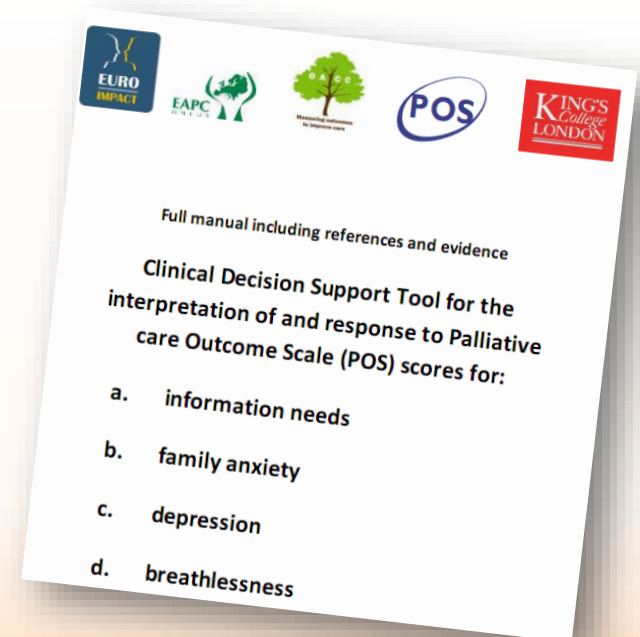
GUIDELINE

Open Access



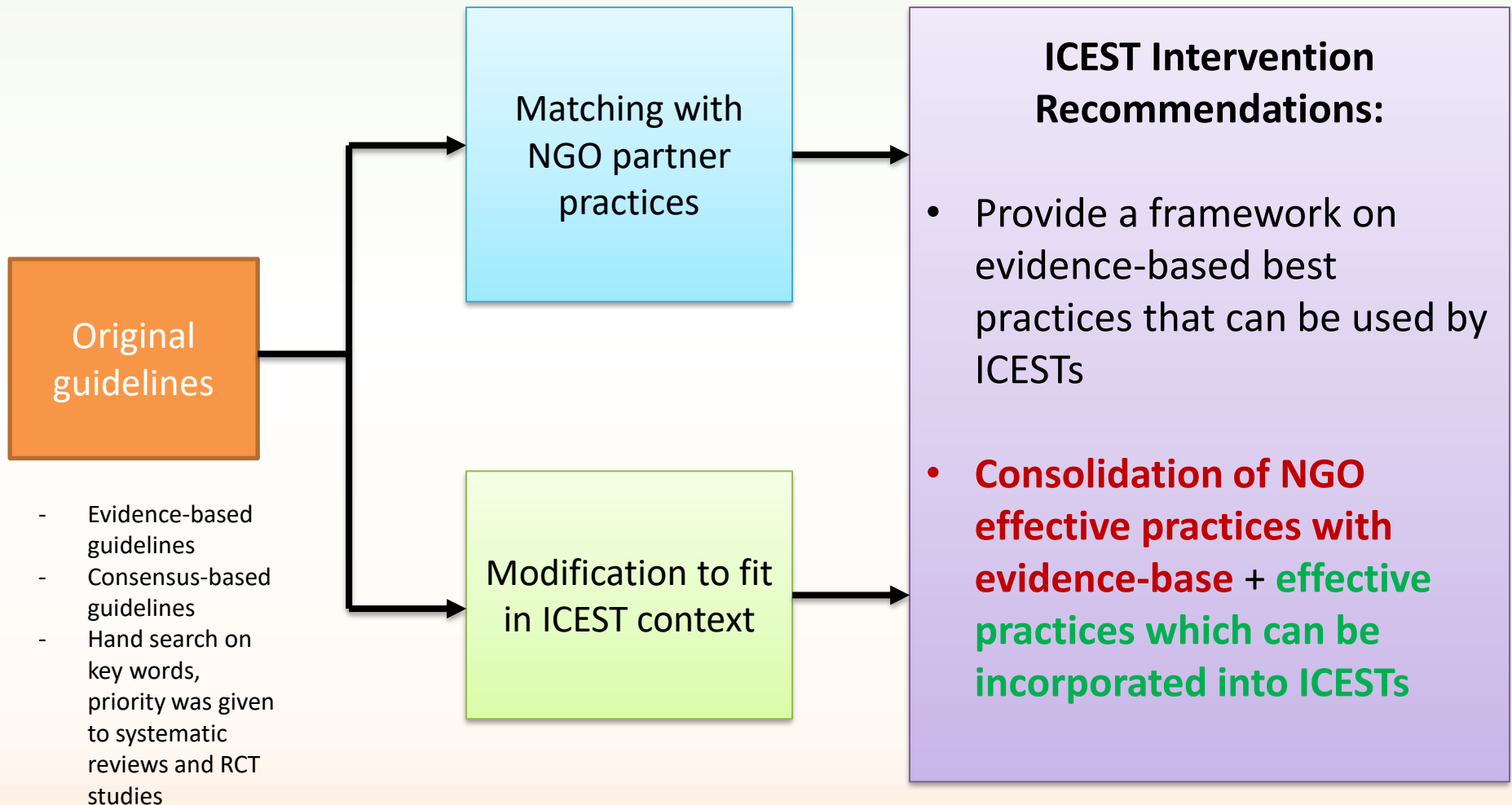
How should we manage information needs, family anxiety, depression, and breathlessness for those affected by advanced disease: development of a Clinical Decision Support Tool using a Delphi design

Liesbeth M. van Vliet^{1*}, Richard Harding¹, Claudia Bausewein², Sheila Payne³, Irene J. Higginson¹
and on behalf of EUROIMPACT



(van Vliet, Harding, Bausewein, Payne, & Higginson, 2015)

ICEST Feature 4: Manualised targeted evidence-based interventions (2)



Patient Anxiety

Specific Interventions			
Level of Needs	Assessment	Intervention	Referral
Very High	A	Conduct psychosocial assessment with GAD-7 (See Appendix 7)	
	I	GAD -7 score below the cut-off of 10 <ul style="list-style-type: none"> Observe continuously & offer Specific Interventions and/or General Supportive Care as recommended below 	
	R	GAD-7 score above the cut-off of 10 <ul style="list-style-type: none"> Seek advice from parent healthcare team on pharmaceutical treatment and psychiatric/ hospital clinical psychology service/ specialist palliative care service referral (Johnson III, 2018) Refer to clinical psychologists for clinical assessment, consultation and follow-up Consider adopting a collaborative care approach if patient is diagnosed severe anxiety and communicate closely with the healthcare team 	
	A	Active monitoring and support <ul style="list-style-type: none"> For patient with severe or very high anxiety, reassess regularly every 2 weeks (European Palliative Care Research Collaborative, 2010). 	
	I	Offer Specific Interventions and/or General Supportive Care as recommended below during watchful waiting period	

Specific Interventions			
Level of Needs	Assessment	Intervention	Referral
High	A	Detect the exhibition of symptoms, intensity and impacts of daily functioning <ul style="list-style-type: none"> Cognitive: difficulty concentrating, unable to focus Emotional & behavioural: easily annoyed, restless, express feelings of worry, crying uncontrollably, yell & scream, repetitive self-soothing behaviors Physical: insomnia, increased heart rate, fast breathing, vomit & nausea, dry mouth, trembling, sweat profusely, abdominal pain Prioritize the cognitive, emotional & behavioral symptoms in the detecting as physical symptoms may be caused by the disease or medical treatment (European Palliative Care Research Collaborative, 2010). Assess possible triggering causes, their adaptive state, the stage of the disease (Clinical practice guidelines in the Spanish NHS & Ministry of health and consumer affairs, 2008) Enquire with both patient and carer(s) 	
		Beware of the comorbidity <ul style="list-style-type: none"> Anxiety usually associates with depression, existential concerns, uncontrolled physical problems, and unresolved practical concerns. 	

High

Should adopt a holistic view in assessment and intervention

Pay attention to personal or family depression history

- Advanced disease is a stressful event which could intensify the existing mental health issues or trigger the recurrence of previous mental illness (European Palliative Care Research Collaborative, 2010).

A

Identify causes of high anxiety (Clinical practice guidelines in the Spanish NHS & Ministry of health and consumer affairs, 2008; McCusker et al., 2020; Zweers, de Graaf, & Teunissen, 2016)

- Non-controlled physical symptoms such as pain (Block, 2000), fatigue, sleep disturbance, nausea, and cardiac arrhythmias (Delgado-Guay et al., 2009; Gilbertson-White, Aouizerat, Jahan, & Miaskowski, 2011; Mystakidou et al., 2005; Stoklosa et al., 2011; Wilson et al., 2009), shortness of breath (Murillo & Holland, 2004).
- Worry about practical arrangements
- Fears induced by uncertainty about future (Murillo & Holland, 2004).
- Isolation, and being dependent (Block, 2000).
- Family-related issues: High family carer's burden, poor mental health of family carers (Jacobs et al., 2017; Li, Lin, Xu, & Zhou, 2018; Oechsle, Goerth, Bokemeyer, & Mehnert, 2013; Soto-Rubio, Perez-Marin, Miguel, & Martin, 2018), and poor family functioning (Areia et al., 2019; Kissane & Bloch, 2002)

Further assessment to identify causes

I

Non-controlled physical symptoms

Timely response to uncontrolled physical symptoms

- It should be a priority intervention if patient expresses such concerns of physical symptoms. Provide symptom control advice and information in a timely manner through visit, phone or telemedicine, and provide scheduled telephone monitoring (Ahluwalia et al., 2018; Head, Schapmire, & Zheng, 2017; Kornblith et al., 2006)
- Communicate with the parent healthcare team and address the physical concerns of patient, including reassessment, proper pharmaceutical treatment and follow up
- Introduce non-pharmacological evidence-based interventions to address the specific symptoms, under the advice of healthcare professionals. Details refer to the symptom specific managements under the section "Patient Physical Symptoms"

R

Report the anxiety symptoms to the parent healthcare team

- Encourage and educate patient to report the anxiety symptoms, if any
- Assess anxiety symptoms, prescribe pharmaceutical treatment e.g. sleeping pills, and arrange follow up if necessary

I

Worry about practical arrangements

Immediate actions to address the practical concerns

- Prioritize and take concrete actions to resolve the situation

Evidence-based practices for individual identified cause

Differentiated interventions

High	<ul style="list-style-type: none"> Include but not limit to volunteer support and referral to community resources.
	Fears induced by uncertainty about future (Murillo & Holland, 2004)
I	<p><u>Guided self-help interventions to relieve stress at home & regain a sense of control (Ahluwalia et al., 2018)</u></p> <ul style="list-style-type: none"> Deep/ Diaphragmatic breathing, guided imagery, progressive muscle relaxation, mild to moderate intense exercise (details of relaxation exercises please see Appendix 10, p.143) Distraction, e.g. joyful activities, art-based activities (Puetz, Morley, & Herring, 2013) Emotional freedom techniques (tapping) (Boath, Stewart, & Carryer, 2012; Coyle, 2017). Resource: https://www.youtube.com/watch?v=O3vKokVHSsA (Expert Village, 2008, January 17) Simple naming games allow patient to feel grounded in the moment
I	<p><u>Help patient to deal with maladaptive thoughts</u></p> <ul style="list-style-type: none"> Cognitive-behavioral Interventions helps patient to understand the automatic negative thoughts can exacerbate emotional difficulties, depression, & anxiety, and influence behaviour (Fulton, Newins, Porter, Ramos, 2018; Grossman, Brooker, Michael, & Kissane, 2018; Horne & Watson, 2011). (details of cognitive behavioral techniques please see Appendix 10, p.143) Use Socratic Questionings to identify the relationship between stressful events, automatic negative thoughts, physiological-emotional-behavioral reactions. Socratic questioning is a guided discovery process (Padesky, 1993). It involves asking questions which: <ul style="list-style-type: none"> patient has the knowledge to answer draw patient's attention to information that is relevant but outside his/her current focus e.g. question trigger the retrieval of information and memories contradictory to his/her current mood and beliefs help patient to either reevaluate a previous conclusion or construct a new idea Consider cognitive techniques such as cognitive restructuring exercises, thoughts diary if the negative thoughts are based on distorted thoughts or interpretations. Empower patient to challenge these maladaptive thoughts (Horne & Watson, 2011). Consider behavioural techniques such as activity scheduling and distraction otherwise or systematic desensitization for phobic anxiety or irrational fears for medical procedures, relaxation exercises for fatigue and chronic pain management (Diefenbach, Tolin, Gilliam, & Meunier, 2008).
	Isolation, and being dependent

General Supportive Care

Score	Assessment	Intervention	Referral
Low	A	Assess regularly (Zweers et al., 2016) <ul style="list-style-type: none"> Enquire actively about patient's concerns/feelings through observation and communication, especially at the points of care transition and disease progression Carer(s) can play an important role in detecting anxiety and depression. Ask them about patient's mood (National Breast Cancer Center & National Cancer Control Initiative [NBCC], 2003). 	
(For No indicated needs, interventions are optional)	I	Maintain rapport <ul style="list-style-type: none"> Active Listening Provide emotional support Communicate openly and provide information (on all topics) in accordance with their preferences and discuss information in appropriate language Validate patient's strength and effort to relieve stress Use communication protocol NURSE to respond to emotion with empathy (See Appendix 10 for more details, p.146) Invite communication with Ask-Tell-Ask (See Appendix 10 p.146 for more details) 	
		Avoid further disruptions in daily activities, promote independency & normalcy <ul style="list-style-type: none"> Try to maintain routines including regular sleeping and waking times, physical and quiet activities Allow patient's participation in deciding daily activities e.g. when, what and how much to eat, and promote a sense of autonomy and dignity Arrange outdoor activities according to patient's energy levels Discuss with healthcare team on treatment methods, home nursing services and consider home modifications to maximize the mobility and functionality 	
	I	Engender positive emotions to enhance resources for coping <ul style="list-style-type: none"> Base on the broaden-and-build theory (Fredrickson, 2001), engaging patient in activities which can engender positive emotions, including joy, interest, contentment and love, can broaden the patient's momentary thought-action repertoire, which can in turn build the patient's personal resources for coping. Arrange leisure activities to patient with an aim to engender happiness, interest, and sense of connection and achievement. Patient's ability and interest should be considered when designing the type of activities. 	
	I	Offer psychoeducation to reassure patient <ul style="list-style-type: none"> Normalize fear and anxiety aroused in the anticipation of death and any uncertainties lie ahead, which may include pain, the treatments and having to rely on others. The changing in patient's roles, identities and functionalities do not diminish his/her worth as a person to be loved and respected 	

Recommendations for low level symptom

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Jockey Club End-of-Life Community Care Project

Findings from Evaluation

策劃及捐助 Initiated and funded by:

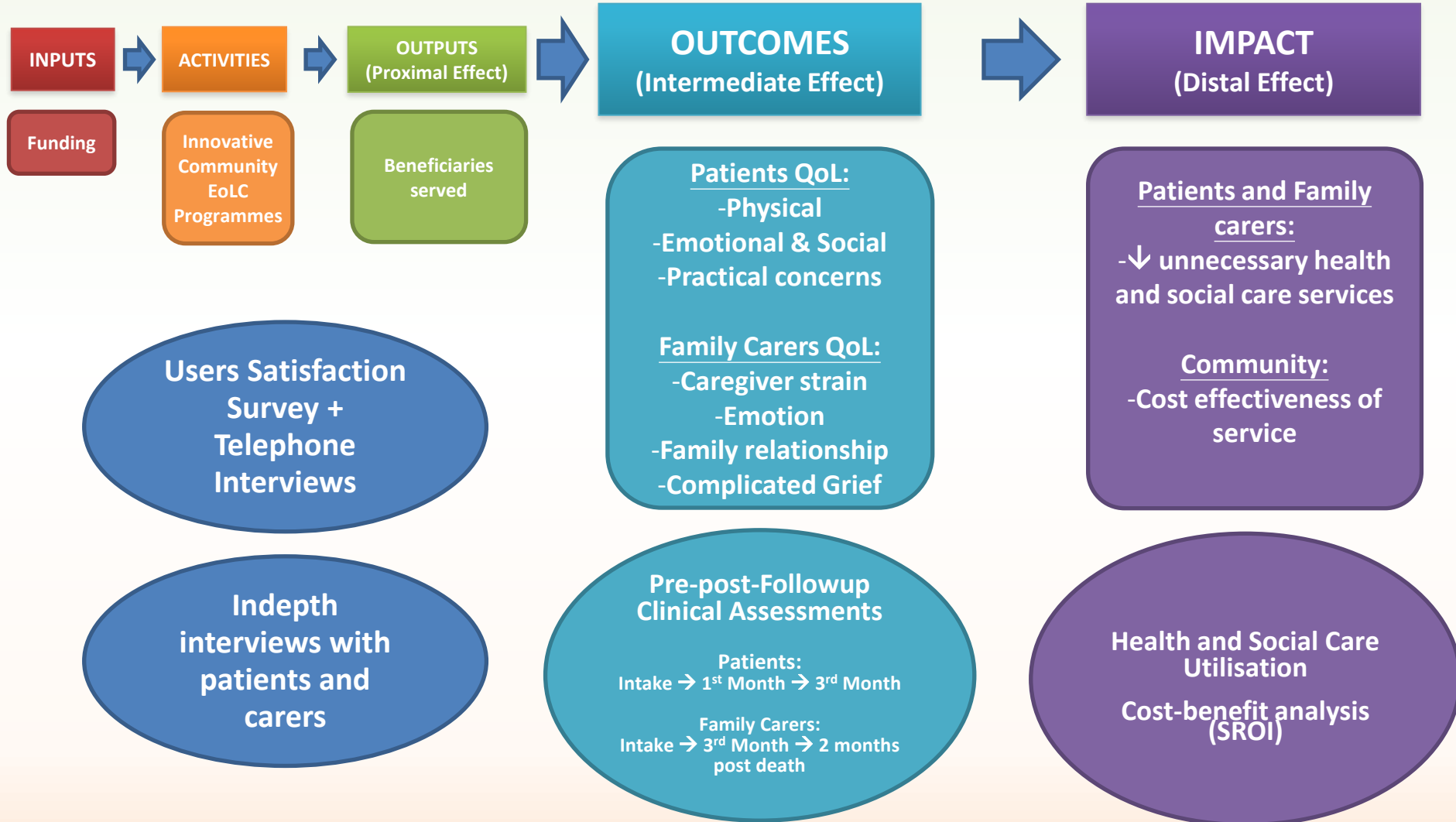


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合作夥伴 Project Partner:



Evaluation Framework and Methods



Standardised Assessment tools

Patients



- Integrated Palliative Care Outcome Scale (IPOS)
- Family relation
- Social distress
- ACP behavior
- Medical service utilization in the last 6 months of life



Family carers



- 13-item Chinese version Modified-Caregiver Strain Index (C-M-CSI) (*Chan, Chan, & Suen, 2013*)
- Patient Health Questionnaire-2 (*Kroenke, Spitzer, & Williams, 2003*)
- Family anxiety (IPOS)
- 19-item Chinese inventory of complicated grief (*Prigerson et al, 1995; Tang & Chow, 2017*)

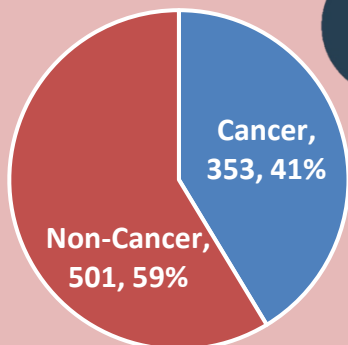
Patients Background

(Jan 1, 2018 – Mar 31, 2021)



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N=854



13.31% with dementia as comorbid or major diagnosis

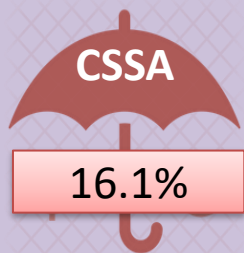
Mean service duration for deceased patients
4.32 (4.647) months

Among 729 patients with intake data:



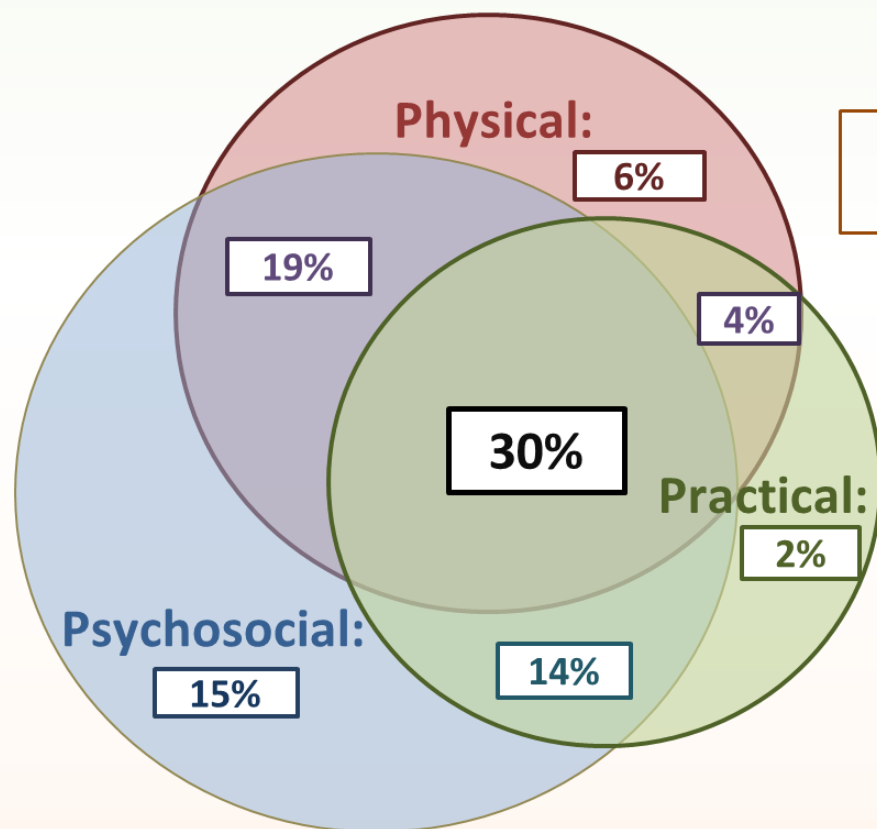
Male
52%

Mean age:
78.41 (11.682) years old



73% living with family
21.12% living alone
(± domestic helper)
2.19% RCHes

% of Patients' Need at Intake (N=598)

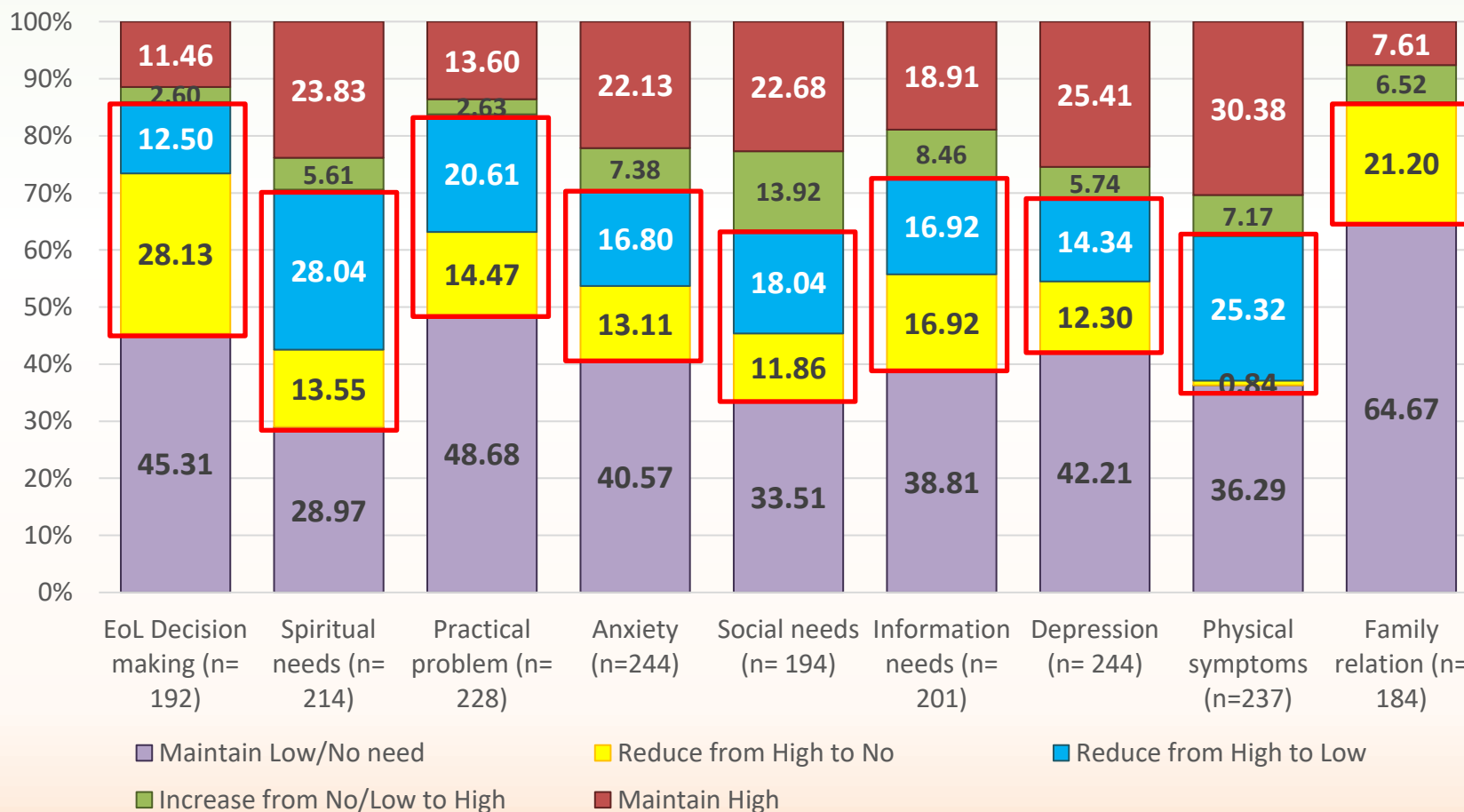


All (3P) Low Needs:
10%

Patients' Changes in Need



Patient 3P need changes in 3 months (N=184-244)

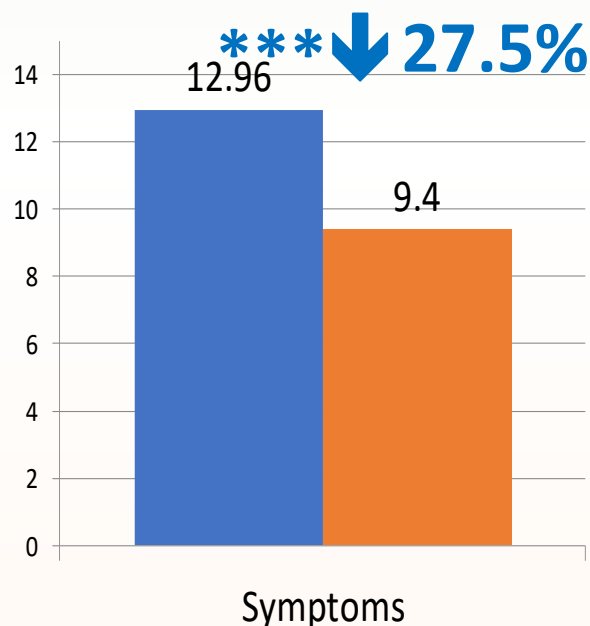


Patient Outcomes - Physical

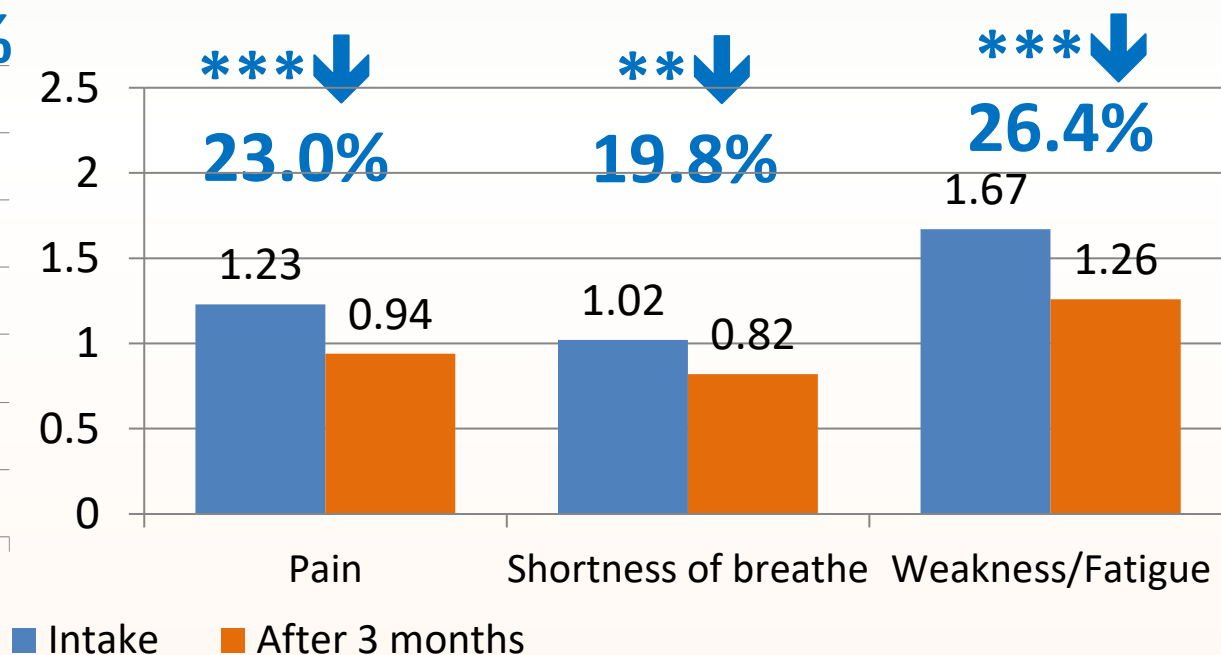
Physical

Patients with Intake and 3-month assessments (N=246)

Physical Symptoms (N=225)



Specific Physical Symptoms (N=232-234)



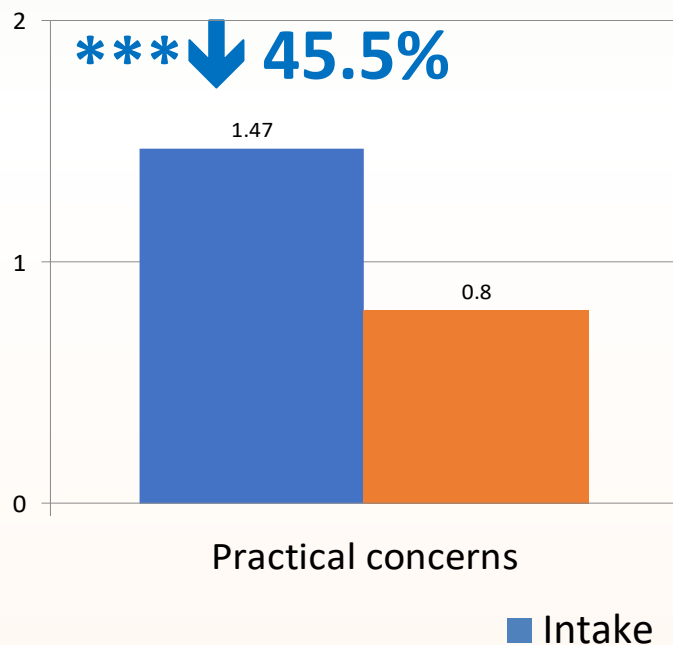
Physical symptoms are measured by Integrated Palliative Care Outcome Scale (IPOS) of King's College with 3 more symptoms added. *** $p < .001$, ** $p < .01$ for paired t-test; The percentages represent the % of changes of mean score between intake and after 3 months. Overall symptom score range between 0-52, with each symptom score between 0-4.

Patient Outcomes - Practical

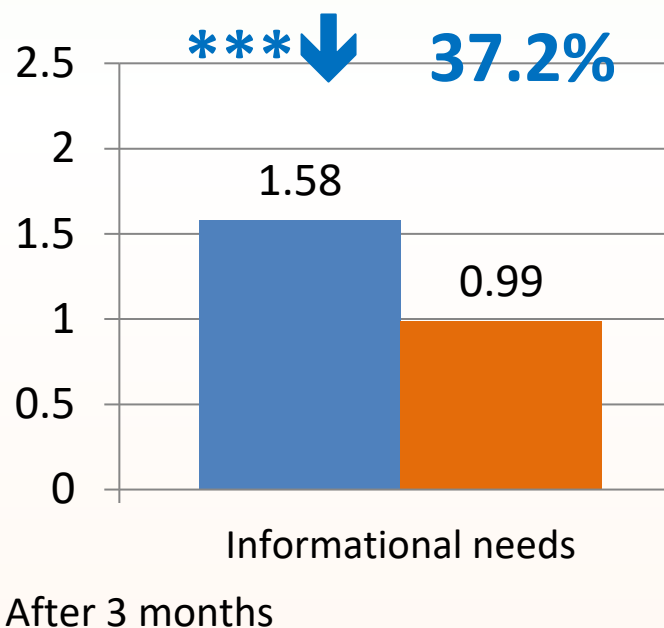
Practical

Patients with Intake and 3-month assessments (N=246)

Practical concerns (N=228)



Unmet Information needs (N=201)



As measured by Integrated Palliative Care Outcome Scale (IPOS) of King's College

*** $p < .001$ for paired t-test; The percentages represent the % of changes of mean score between intake and after 3 months
All items are measured on a 0-4 point scale, with higher scores indicate higher needs or more severe problem.

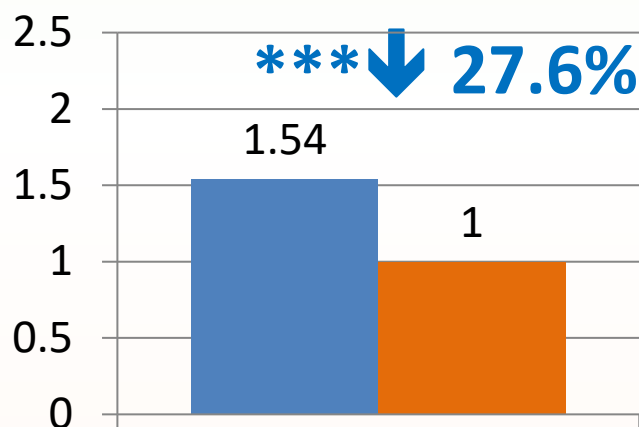
Patient Outcomes - Psychosocial

Social

Patients with Intake and 3-month assessments (N=246)

Family relational problem

Mean score [3 items] (N=184)



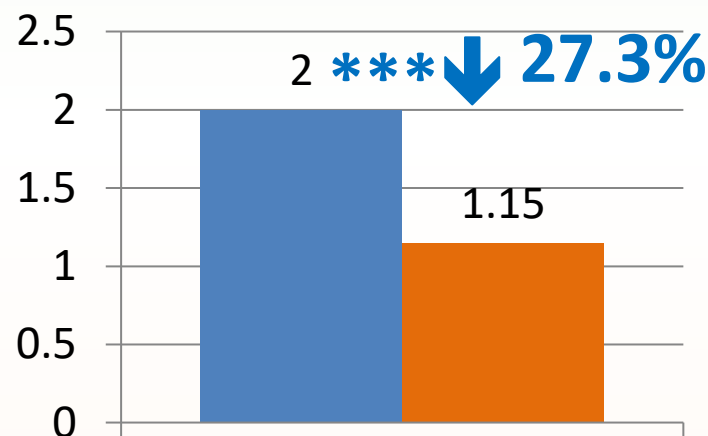
Family relational problems

Experiencing problems with/lacking:

- Mutual support and care in family (-32.7%)
- Openly express thoughts and feelings (-30.8%)
- Conflicts between family members (-15.0%)

Social support need/loneliness

Mean score [3 items] (N=194)



Social support need/loneliness

Experiencing problems with/lacking:

- Felt lonely (-40.2%)
- Have many people to rely on (-33.3%)
- Want to be with someone (-13.8%)

■ Intake ■ After 3 months

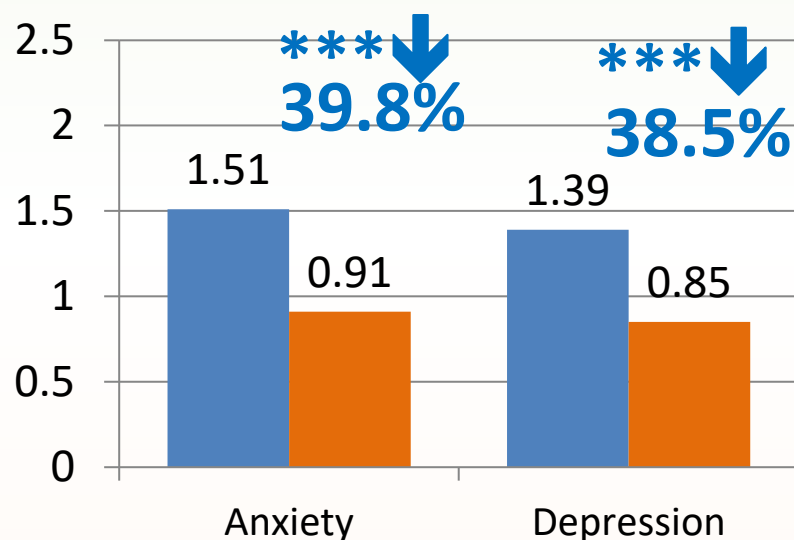
*** $p < .001$ for paired t -test; The percentages represent the % of changes of mean score between intake and after 3 months
All items are measured on a 0-4 point scale, with higher scores indicate higher needs or more severe problem.

Patient Outcomes – Psychosocial

Psychological

Patients with Intake and 3-month assessments (N=246)

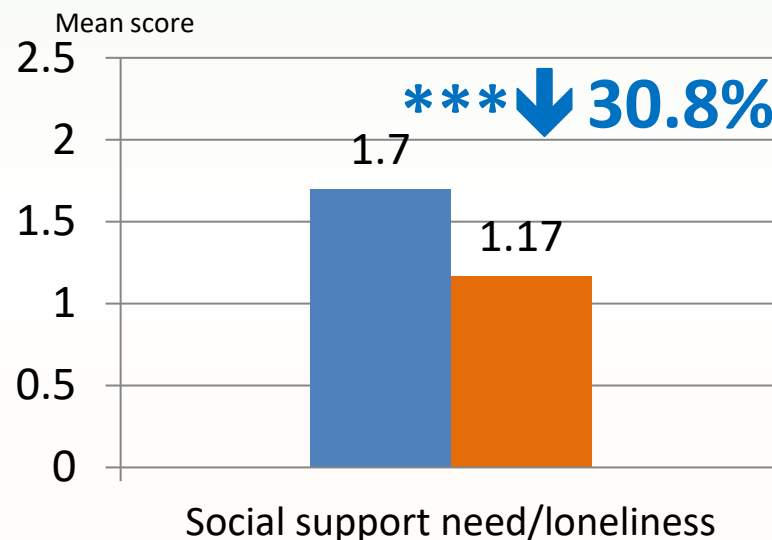
Psychological distress (N=217)



■ Intake
■ After 3 months

**p<.05 for paired t-test; The percentages represent the % of changes of mean score between intake and after 3 months. All items are measured on a 0-4 point scale, with higher scores indicate higher needs or more severe problem.*

Spiritual distress [6 items] (N=214)



A lack of/experiencing distress with (Spiritual)

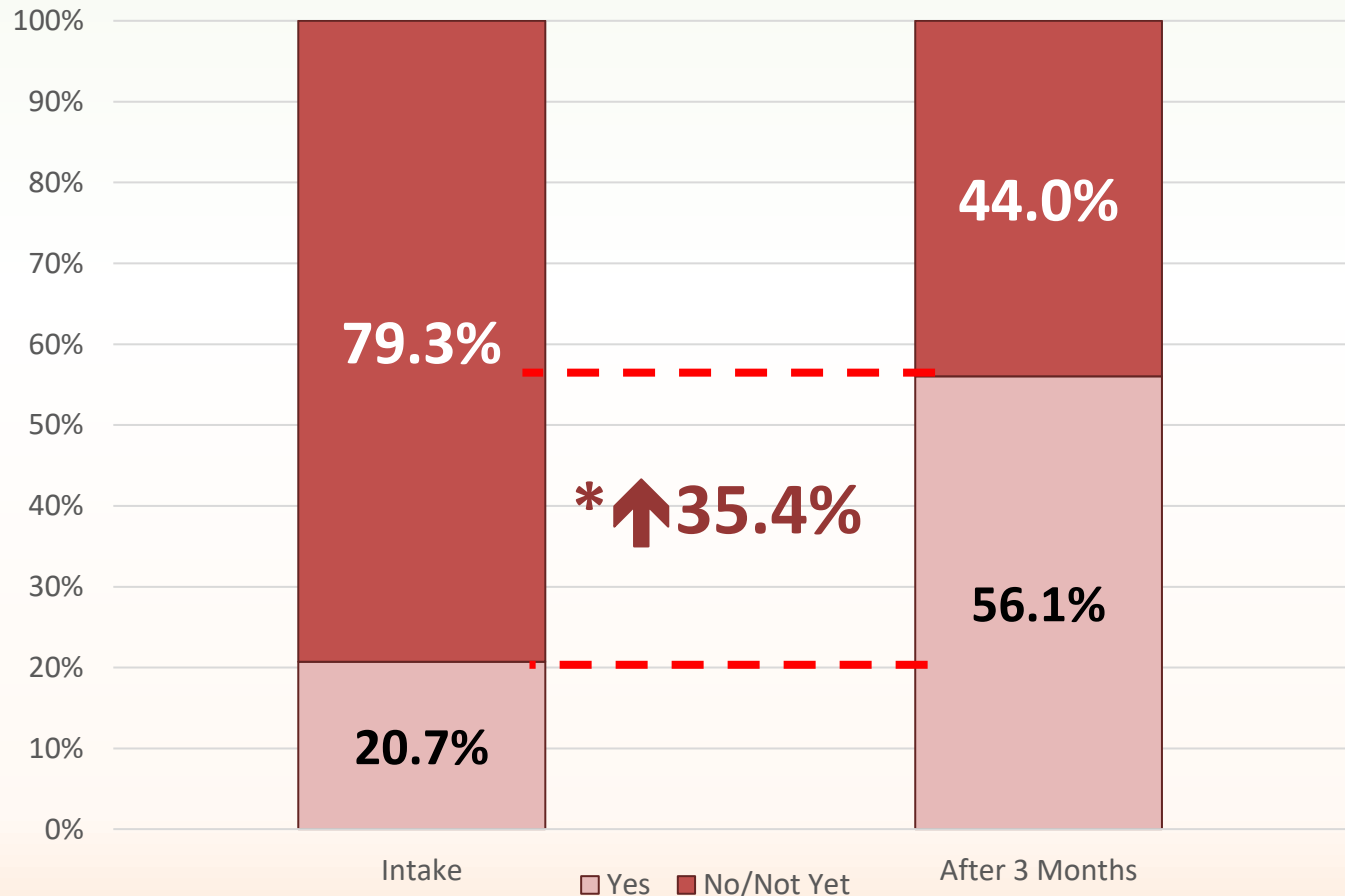
- Worried about afterlife (-46.9%)
- Have unfinished businesses (-38.5%)
- Satisfied with life (-36%)
- Felt at peace (-31.5%)
- Felt oneself a burden to family (-30%)
- Have meaning in life (-28%)
- Felt hopes in life (-23.4%)

Patients' Specific Changes

End-of-Life Care Decision Making



Patients' ACP Behavior (N=198)



Note. * $p < .05$ in Wilcoxon Signed Ranks Test refers to the significant difference between the patients' assessment at intake and 3-month later.

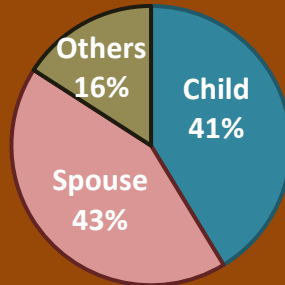
Carers Background

(Jan 1, 2018 – Mar 31, 2021)



N=729 (Those with T0)

Female
(72.4%)



37.1%
working

Mean Age:
59.86 (14.277)



Providing on average

64.42 (57.729) hours of care per week

Accompany patient to clinics/ hospital for **2.08 (3.068)** days per month



0.87 (2.178) times of seeing a doctor/medical specialist in the last month for themselves

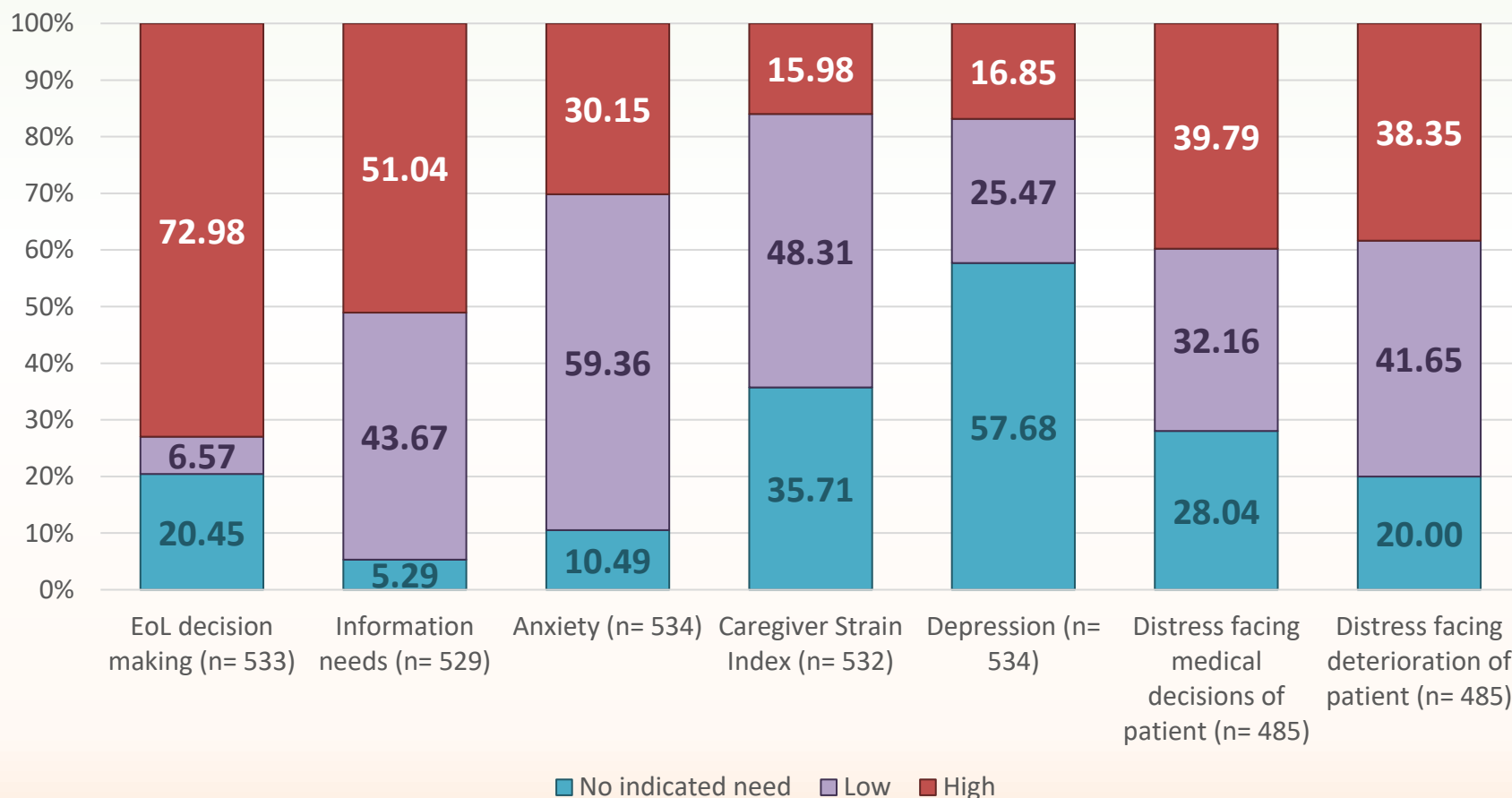
0.94 (3.781) days being unable to take care of the patient because of sickness in the past month



Carers' Needs at intake



Carers' Needs at Intake (N=485 – 534)

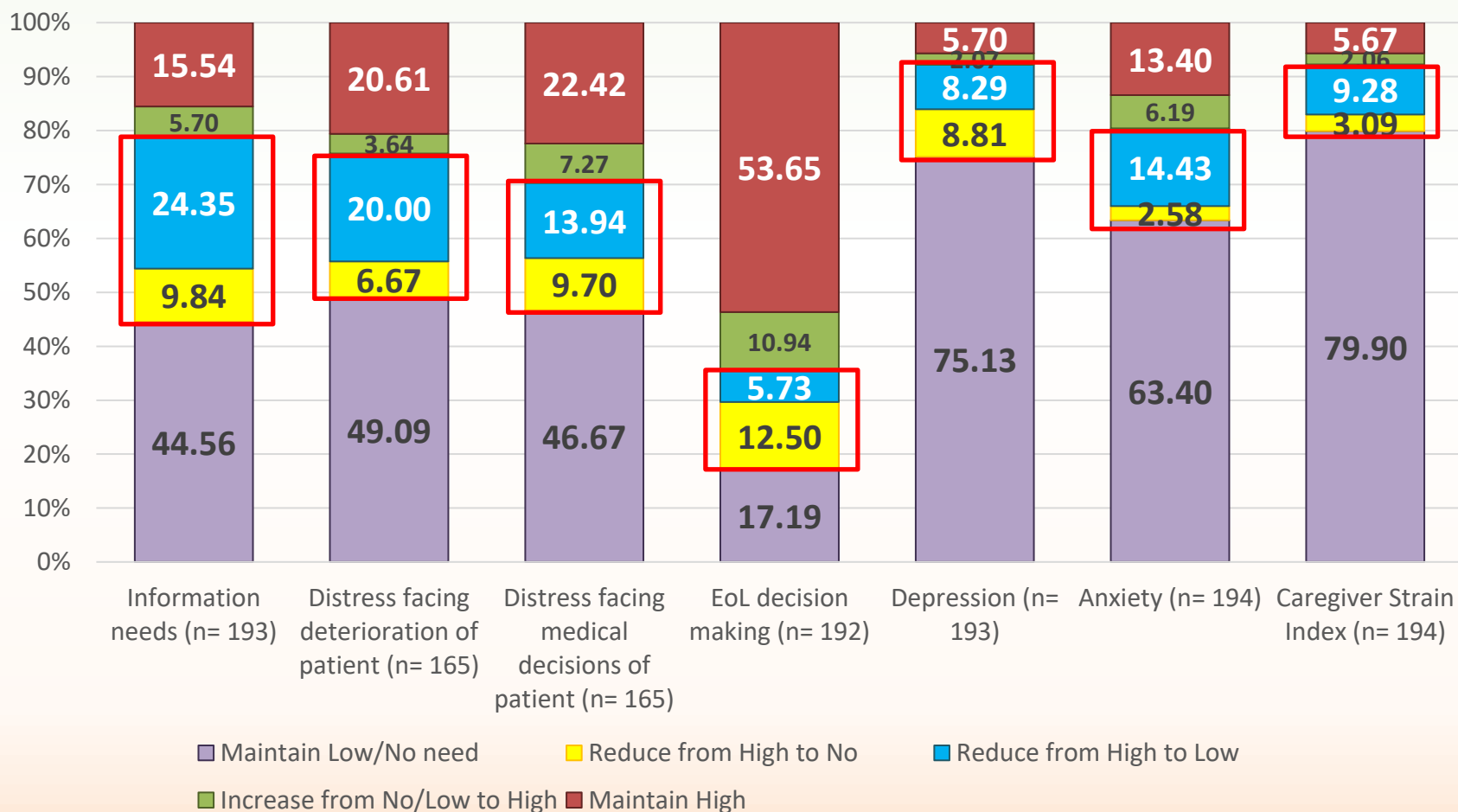


Note. All caregivers with TO assessments

Carers' Changes in Needs



Carer 3P Need Changes in 3 Months (N=165 – 194)

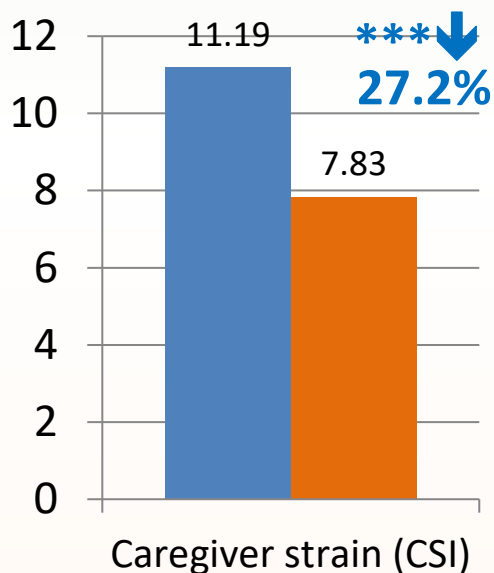


Caregiver Outcomes - Practical

Practical

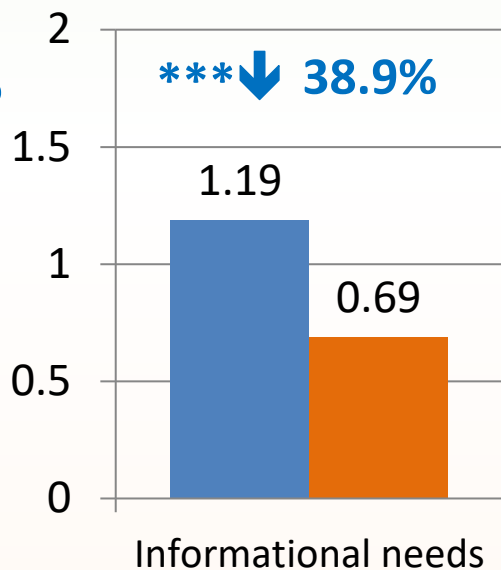
Caregivers with Intake and 3-month assessments (N=198)

Caregiver Strain (N=194)



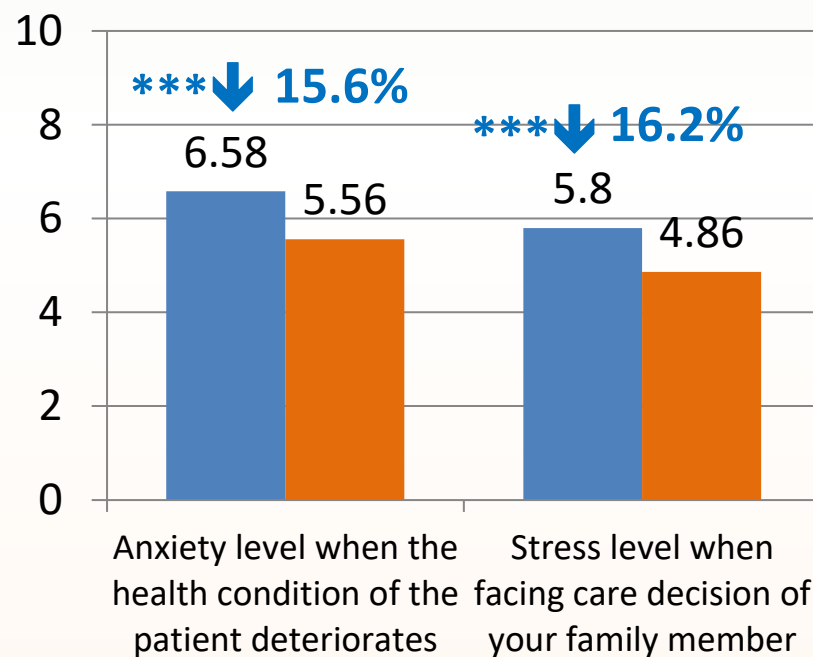
■ Intake

Information need (N=193)



■ After 3 months

Decision-making & crisis-induced stress (N=165)



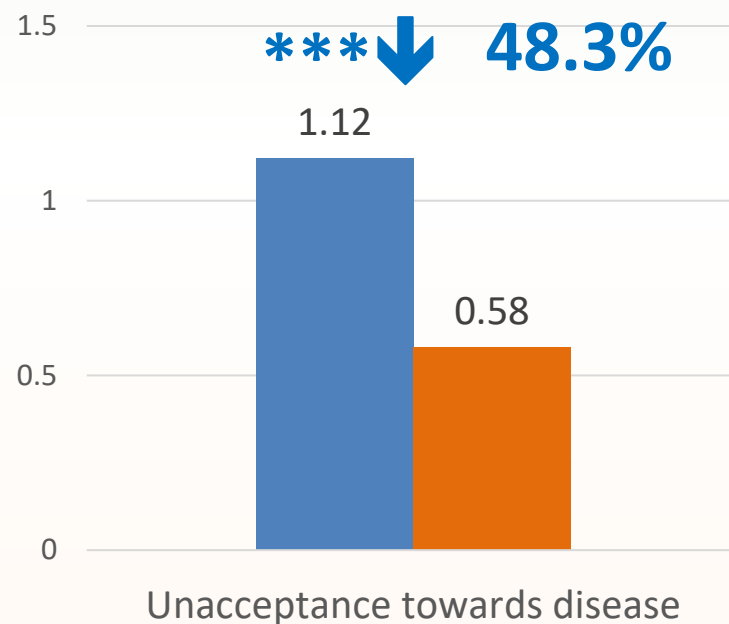
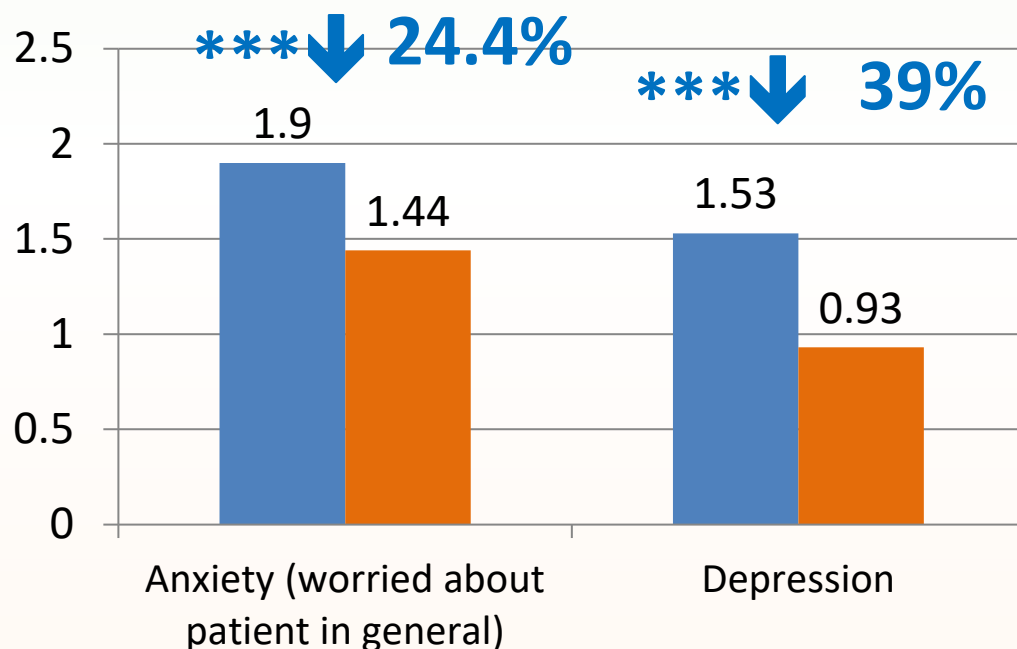
*** $p < .001$ for paired t -test; The percentages represent the % of changes of mean score between intake and after 3 months. Caregiver strain has a score range of 0-26, informational needs range between 0-4, decision-making & crisis induced-stress has a score range between 1 and 10. Higher scores indicate greater problem/higher needs.

Caregiver Outcomes – Psychosocial

Psychological

Caregivers with Intake and 3-month assessments (N=198)

Psychological distress (N=194)



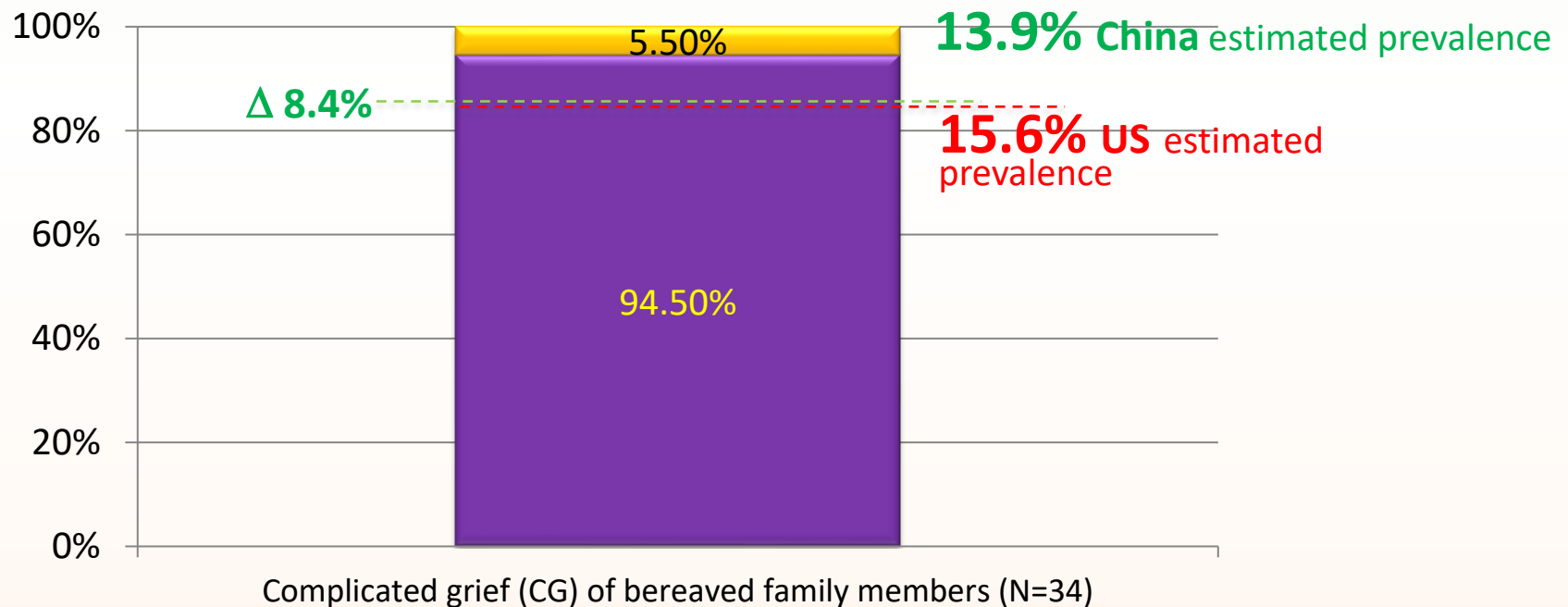
***p<.001 for paired t-test; The percentages represent the % of changes of mean score between intake and after 3 months. Anxiety (worried about patient in general) is measured with IPOS (score range: 0-4), depression was measured with the Patient Health Questionnaire-2 (range: 0-6)

Grief

Caregivers with bereavement assessments (N=182)

Bereavement outcomes of family members (N=182)

- High risk group (scored above 25 on the inventory of complicated grief)
- Low risk group (scored 25 or below on the inventory of complicated grief)

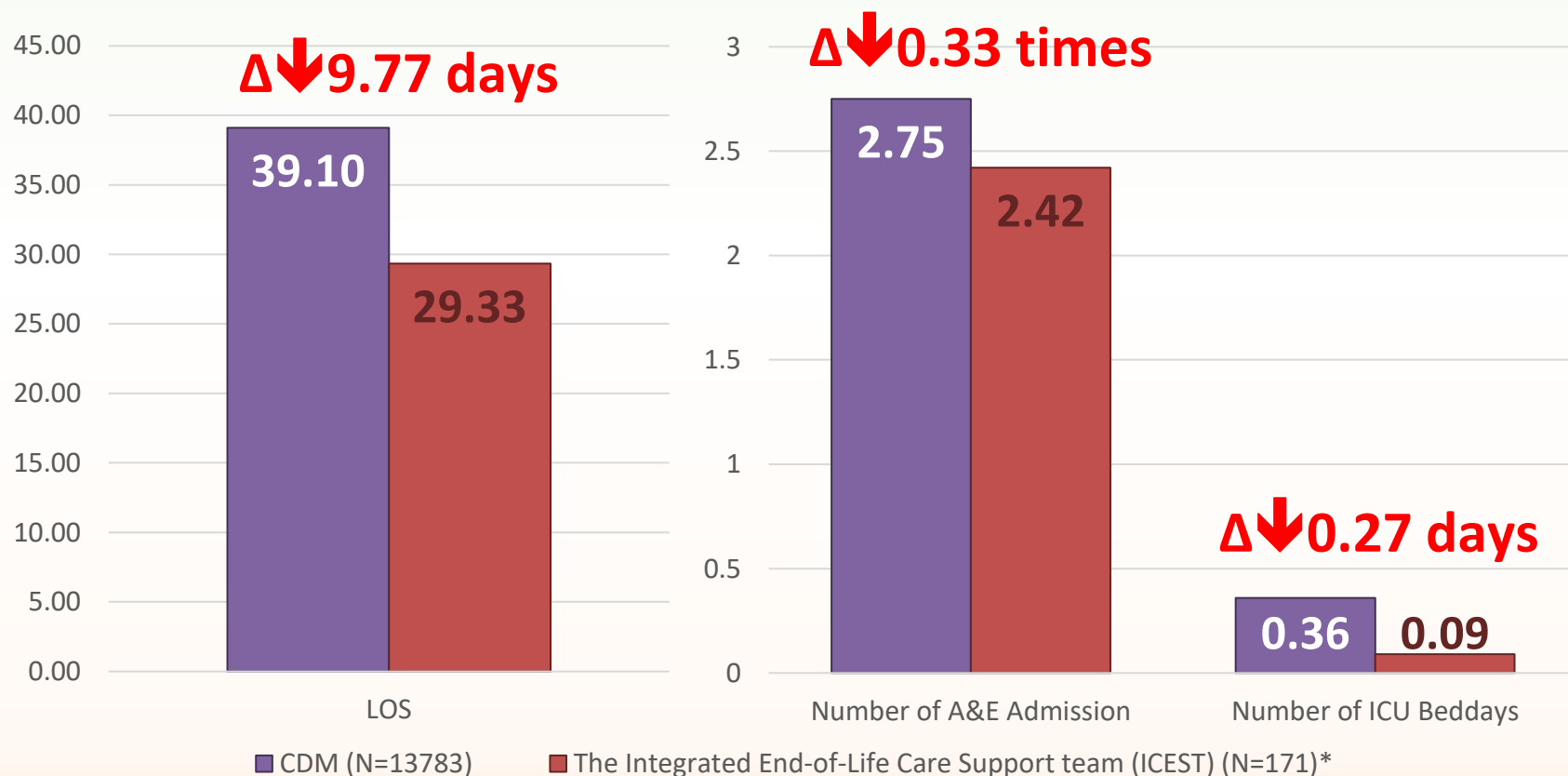


Service Impact:



Medical Service Usage in the Last 6 Months of Life per patient

Comparison Between Patients in ICEST and Patients in General in the Utilization of Medical Services¹ in the Last 6 Month of Life (N=171)



¹ The University of Hong Kong obtained data of the medical services in the last 6 months of life among patients who died of cancer, chronic obstructive pulmonary disease, heart failure, end-stage renal disease, motor neuron disease, and Parkinson's disease from the central database of Hospital Authority. After clinical data mining, the impact of the project on patients' use of medical services was evaluated through comparing with the data of six-month before the death of patients.

Impact: Cost-benefit Analysis

Social Return on Investment

The aim of SROI:

- Find out how much value has been created (and **for whom**) by our EoLC program by translating social objectives into financial measures.

Essential elements of SROI:

- Identify stakeholders (people/organizations that experience changes as a result of the EoLC program)
- Identify inputs (resources required to deliver the activities)
- Identify the changes (outcomes) experienced by the stakeholders

SROI outcome:

- Cost-benefit analysis:** a ratio of benefits to costs of achieving those benefits (e.g. a SROI ratio of 4:1 means for every dollar invested in EoLC, a social return of \$4 was generated)

$$\text{SROI} = \frac{\text{Net Present Value of Benefits}}{\text{Net Present Value of Investment}}$$

Two-stages research

Consensus workshops with health and social care experts (n=17)

- To identify stakeholders of the ICEST activities
- To delineate the inputs of the ICEST activities
- To identify outcomes of the ICEST activities on stakeholders
- To propose the service and number of service session required to achieve the outcomes

Outcome identified and further refine the valuation on high level of symptoms/problems by...

2-round Delphi study with larger panels of:

- Health and social care professionals (n=40)
- EoLC volunteers (n=17)

Outcome identified and further seek consensus on valuation on low level of symptoms/problems by...

Individual interview with:

- Patient (n=6) and family carers (n=6)

Calculating SROI (1)

PATIENT OUTCOMES	Projected Quantity	financial proxy	attribution	Deadweight/Displacement/Drop-off	Values
pain 3->2	77	\$ 1,954.40	28.0%	0	\$ 42,136.86
pain 4->3	22	\$ 24,080.00	28.0%	0	\$ 148,332.80
pain 4->2	11	\$ 26,034.40	28.0%	0	\$ 80,185.95
shortness of breath 3->2	48	\$ 2,083.20	28.0%	0	\$ 27,998.21
shortness of breath 4->3	22	\$ 25,163.60	28.0%	0	\$ 155,007.78
shortness of breath 4->2	18	\$ 27,246.80	28.0%	0	\$ 137,323.87
weakness 3->2	107	\$ 2,503.20	28.0%	0	\$ 74,995.87
weakness 4->3	22	\$ 30,581.60	28.0%	0	\$ 188,382.66
weakness 4->2	40	\$ 33,084.80	28.0%	0	\$ 370,549.76
other physical symptoms 3->2	228	\$ 2,072.00	28.0%	0	\$ 132,276.48
other physical symptoms 4->3	33	\$ 24,983.00	28.0%	0	\$ 230,842.92
other physical symptoms 4->2	144	\$ 27,055.00	28.0%	0	\$ 1,090,857.60
practical and social needs 3->2	223	\$ 758.10	55.0%	0	\$ 92,980.97
practical and social needs 4->3	15	\$ 813.20	55.0%	0	\$ 6,708.90
practical and social needs 4->2	48	\$ 1,571.30	55.0%	0	\$ 41,482.32
emotional symptoms 3->2	186	\$ 6,438.60	96.0%	0	\$ 1,149,676.42
emotional symptoms 4->3	16	\$ 6,307.20	96.0%	0	\$ 96,878.59
emotional symptoms 4->2	47	\$ 12,745.80	96.0%	0	\$ 575,090.50
Total					\$ 4,641,708.45

Notes. Attribution was estimated by calculating the ratio between hours of other community services received by patient to hours of ICEST services of respective type received by patients. No deadweight is assumed as patients are supposed to deteriorate; No displacement was informed; As service last within a year, drop-off is irrelevant. Patients' service hours were not overlapped or shared with caregivers' to avoid double-counting.

Calculating SROI (2)

	Projected Quantity	financial proxy	attribution	Deadweight/Displacement/Drop-off	Values
caregiver strain index 2->1	230	3037.7	0.99	0	691684.29
caregiver strain index 2->0	239	3037.7	0.99	0	718750.197
bereavement risk (over25->under 25)	69	5913	1	0	407997
Total					1818431.487

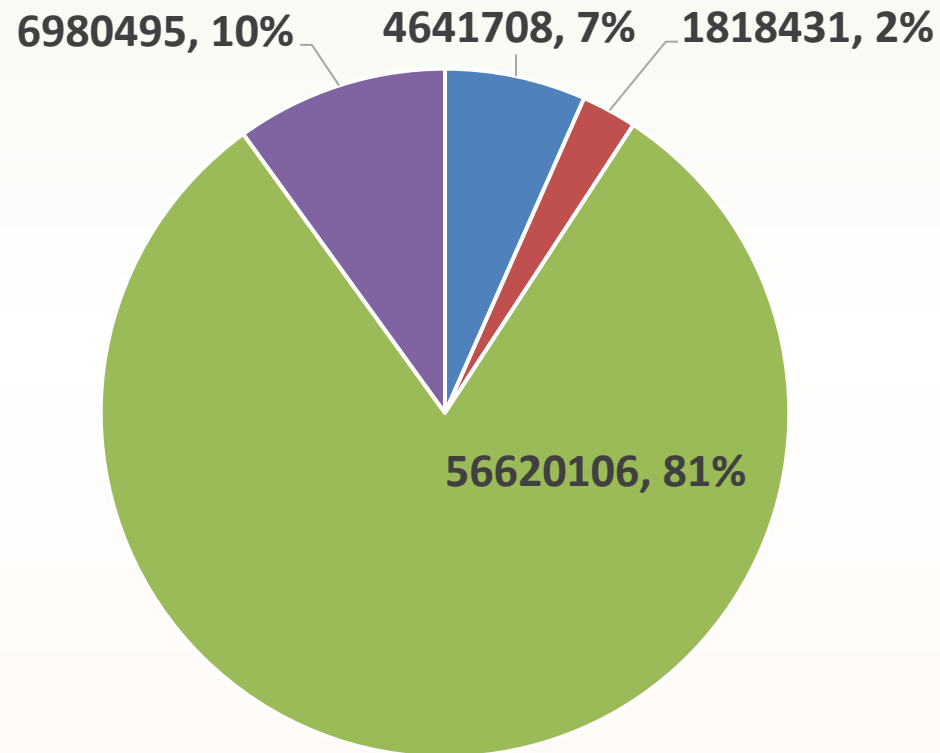
Reduction of medical health service utilization in the last 6 months of life	Averaged reduced # of use	Financial proxy	Values
A&E (times)	0.33	\$ 1,780.00	\$ 503,989.20
ICU (# bedday)	0.27	\$ 24,400.00	\$ 5,652,504.00
Length of stay (# bedday)	9.77	\$ 6,020.00	\$ 50,463,613.20
Total			\$ 56,620,106.40

Notes. Attribution was estimated by calculating the ratio between hours of other community services received by caregivers to hours of ICEST services of respective type received by caregivers. No deadweight is assumed as caregivers are supposed to face more challenge when patients are approaching death; No displacement was informed; As service last within a year, drop-off is irrelevant. Patients' service hours were not overlapped or shared with caregivers' to avoid double-counting.

Calculating SROI (3)

If you have HKD 100 per month, how much are you willing to pay in order to have...	Mean	Median monthly household income for single person household	financial proxy	Averaged per volunteer changes reported	No. of volunteers	attribution (hours)	Deadweight /Displacement/Drop-off	Values
One point of improvement in EoLC knowledge and skills out of 10 points?	23.03	20000	\$ 4,606.00	0.5055	230	0.8	0	\$ 428,413.27
One point of improvement in integrated body-mind-spiritual wellbeing out of 10 points?	29.35	20000	\$ 5,870.00	0	230	0.4	0	\$ -
One point of improvement in death anxiety out of 5 points?	26.65	20000	\$ 5,330.00	0.125	230	0.6	0	\$ 91,942.50
Total								\$ 6,980,495.71

Notes. Attribution was estimated through the qualitative comments given by volunteers in previous focus group studies, which suggested that the EoLC training provided to them and the experience with EoLC was unique to them which could hardly be provided in other types of volunteer work. No strong evidence to suggest deadweight and displacement; As the calculation focuses on impact within a year, drop-off is irrelevant.



■ Patients ■ Caregivers ■ Healthcare service utilization ■ Volunteers

Calculating SROI (4)

Input of \$ 23,655,770 ¹



Preliminary Output ¹

Patient outcomes: \$ 4,641,708

+

Caregiver outcomes: \$ 1,818,431

+

Healthcare service utilization reduction:

\$ 56,620,106

+

Volunteer outcomes: \$ 6,980,496

Sum: \$ 70,060,742

SROI Ratio= 2.96: 1

¹ This is the JCECC project budget for 3 ICESS NGOs between 2018 Jan and 2021 March 31. Output was estimated by projecting the quantity of changes to full sample between the same period (2018 Jan and 2021 March 31). This is a temporary result as data collection is still underway.

- ICESTs – a manualised community-based EoLC model:

Right
care &
Right
Time

- Effective in improving the QoL of patients
- Effective in reducing the stress of family caregivers
- Offered a satisfying EoLC experiences to patients and family caregivers

Right
Place

- Respected patients' wishes to stay in community
- Cost effective & Sustainable

- Autonomy to participation
- Attribution
- Difficulties to conduct RCTs
- Use of brief assessment tools
- Evaluating complex interventions that involve collaboration between various stakeholders

+ Process evaluation

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