Original Article

A pilot study to evaluate the feasibility and potential effectiveness of an early palliative care model: "Educate, Nurture, Advise, Before Life Ends for Singapore"

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Abstract

Objective. The main objective was to pilot the culturally adapted "Educate, Nurture, Advise, Before Life Ends" for Singapore (ENABLE-SG) model to evaluate its feasibility and potential effectiveness.

Methods. A single-arm pilot trial of ENABLE-SG among patients with advanced solid tumors and caregivers of these patients was conducted in the outpatient oncology clinic setting. Enrolled participants participated in individual ENABLE-SG psychoeducational sessions weekly. Patients had 6 sessions on the topics of maintaining positivity, self-care, coping with stress, managing symptoms, exploring what matters most and life review. Caregivers had 4 sessions on the topics of maintaining positivity, self-care, coping with stress and managing symptoms. At baseline, 4, 8, and 12 months after enrolment, patient's quality of life was measured using the Functional Assessment of Chronic Illness Therapy – Palliative Care, patient's mood was measured using the Center for Epidemiologic Studies – Depression scale, and caregiver quality of life was measured using the Singapore Caregiver Quality of Life Scale.

Results. We enrolled 43 patients and 15 caregivers over a 10-month period from August 2021 to June 2022. Although there was a low approach-to-participation rate, most of those who enrolled completed all ENABLE-SG sessions – 72% for patients and 94% for caregivers. Caregivers had better quality of life over time, specifically in the subscales of mental well-being and experience-meaning.

Significance of results. Based on findings from this study, we are planning a randomized waitlist-controlled trial of ENABLE-SG for patients with advanced cancer and their caregivers.

Introduction

Current models of interdisciplinary specialist palliative care focuses on supporting patients with advanced cancer who have complex problems in the last weeks of life (Hui and Bruera 2020). This model has 2 big problems: First, palliative care is delivered very late in the patient's disease trajectory. Second, as the initiation of palliative care is triggered by uncontrolled symptoms typically in a time of crisis, patients and families are often in distress and end up being passive recipients of services (Block and Billings 2014). Models of palliative care ought to move beyond the current reactionary illness–stress paradigm to a proactive health-wellness approach that is integrated early in the patient's serious illness trajectory (Wagner 1998; Wagner et al. 2001).

"Early palliative care" can be broadly defined as dedicated palliative care services that are delivered early in the disease course and concurrent with active treatment (Ferrell et al. 2017). A proactive early palliative care telehealth model, ENABLE (Educate, Nurture, Advise, Before Life Ends), was developed in the U.S. to enhance the coping of patients with advanced cancers and their family caregivers (Bakitas et al. 2009a, 2004). Structured telephonic, psychoeducational sessions are conducted to separately coach patients and caregivers on how to cope effectively with serious illness via developing self-management skills, including problem-solving, decision-making, advance care planning, symptom management, self-care, communication, and life review (Bakitas et al. 2009b, 2009a, 2004; Maloney et al. 2013). In the U.S., a series of randomized controlled trials of ENABLE showed better quality of life and better mood at 3–6 months for patients with advanced cancer and their caregivers, and longer median survival compared to usual care among patients (Bakitas et al. 2015; Dionne-Odom et al. 2015).

Although ENABLE has demonstrated effectiveness in the U.S., we do not know whether or not ENABLE would be effective when implemented in contexts that have different organizational, social, and cultural norms (Skivington et al. 2021). We culturally adapted ENABLE for the Singapore context through a qualitative formative evaluation (Akyar et al. 2018; Yang et al. 2021). The aim of this study was to pilot the adapted ENABLE-SG model, conducted in English, in order to evaluate its feasibility and potential effectiveness.

Methods

This was a single-arm pilot trial of ENABLE-SG among patients with advanced solid tumors and caregivers of these patients, reported according to relevant items in the CONSORT 2010 statement: extension to randomized pilot and feasibility trials (Eldridge et al. 2016). Participants were recruited from the oncology and palliative care outpatient clinics of the National Cancer Centre Singapore (NCCS). NCCS is the largest provider of public cancer care in Singapore, with about 150,000 patient visits per year. Patient eligibility criteria included the following: patients (i) diagnosed with a stage IV solid tumor cancer; (ii) aged 21 years and over; and (iii) able to converse in English. Caregiver eligibility criteria included the following: (i) self-endorsing caring for a family member with stage IV solid tumor cancer; (ii) aged 21 years and over; and (iii) able to converse in English. Patients and family caregivers were not dyads. There was no limitation on the time since diagnosis. This study was approved by the SingHealth Centralised Institutional Review Board (Reference No. 2018/2905)

ENABLE-SG intervention

Enrolled participants participated in individual ENABLE-SG psychoeducational sessions conducted by a palliative care nurse in English. Patients had 6 sessions on the topics of maintaining positivity, self-care, coping with stress, managing symptoms, exploring what matters most and life review. Caregivers had 4 sessions on the topics of maintaining positivity, self-care, coping with stress and managing symptoms. The topics covered by the ENABLE-SG sessions are based on essential elements of palliative care (Figure 1). All sessions began with screening for distress using the distress thermometer and problem list. If the participant was distressed by a specific problem, the nurse may change the order of the session topics. The nurse aimed to conduct the sessions weekly; however, this was subject to availability of participants and whether they felt well enough to proceed with the session.

Study procedures

Written informed consent was obtained from all participants. Research coordinators administered patient-reported outcome measures by telephone at baseline, 4, 8, and 12 months. Demographic and clinical data were extracted from the electronic health records.

Study outcomes

For patients, quality of life was measured using the 46-item Functional Assessment of Chronic Illness Therapy – Palliative Care (FACIT-Pal), comprising physical, emotional, social, functional well-being and additional concerns subscales; score range 0–184, where higher scores indicate better quality of life. Mood was assessed by the 20-item Center for Epidemiologic Studies – Depression scale (CES-D); score range 0–60, where higher scores indicate greater depressed mood and a cut-off score of 18–22 could be used to identify patients at risk of being depressed (Dozeman et al. 2011; Zhang et al. 2015).

For caregivers, quality of life was measured using the locally developed 15-item version of the Singapore Caregiver Quality of

Patients	Caregivers	Topics covered		Elements of palliative care
Session 1 Maintaining positivity	Session 1 Maintaining positivity	-	Handling problems with a positive attitude	- Improving symptom relief and function
		-	A problem-solving attitude	- Psychosocial and spiritual care
		-	The seven steps of problem-solving	
Session 2 Self-care	Session 2 Self-care	-	Healthy eating and nutrition	- Improving symptom relief and function
		-	Exercise	
		-	Quitting smoking	
		-	Sexuality	
		-	Work and family	
Session 3 Coping with stress	Session 3 Coping with stress	-	Coping with stress	- Psychosocial and spiritual care
		-	Spirituality	
		-	Getting the support you need	
Session 4 Managing symptoms	Session 4 Managing symptoms	-	Managing symptoms	- Improving symptom relief and function
		-	Common symptoms in cancer	
		-	Common thoughts and feelings	
Session 5 Talking about what matters most and making choices	-	-	Talking with your family and healthcare providers	- Enhancing communication, values-based treatment and goals of care conversations
		-	Core values: what matters most	
		-	Decision aids: making choices that are right for you	
Session 6 Life review	-	-	Starting a conversation about your journey	- Psychosocial and spiritual care
		-	Looking at today, looking at tomorrow	
		-	Creating a legacy	

Figure 1. Topics and elements of palliative care covered by ENABLE-SG sessions.
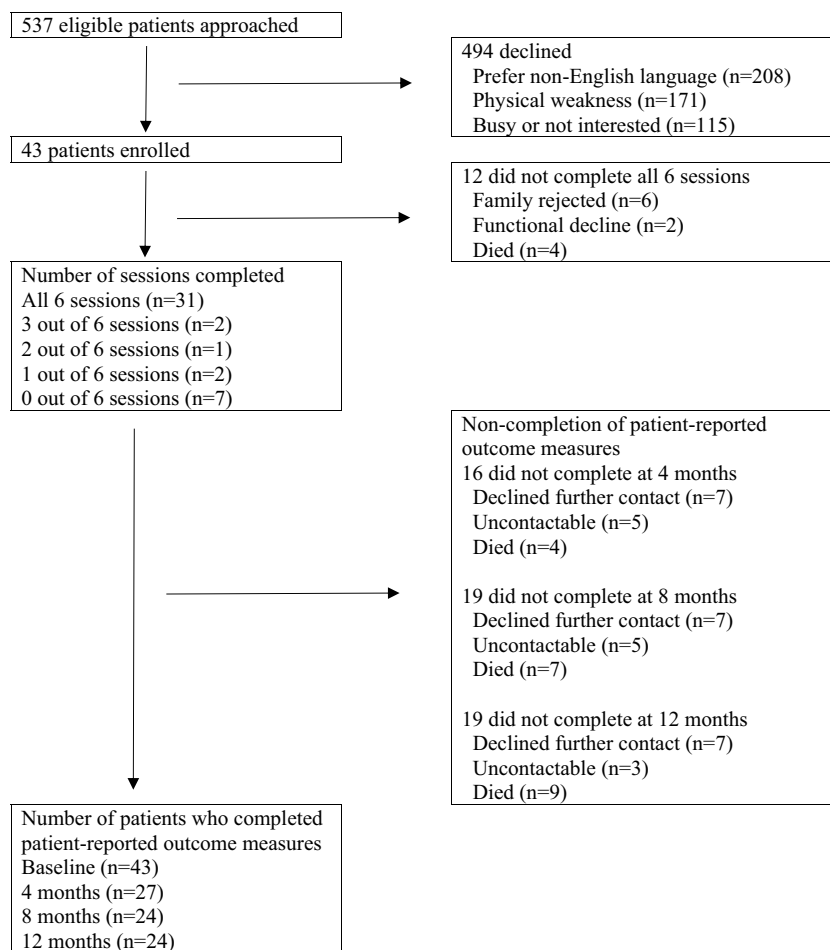
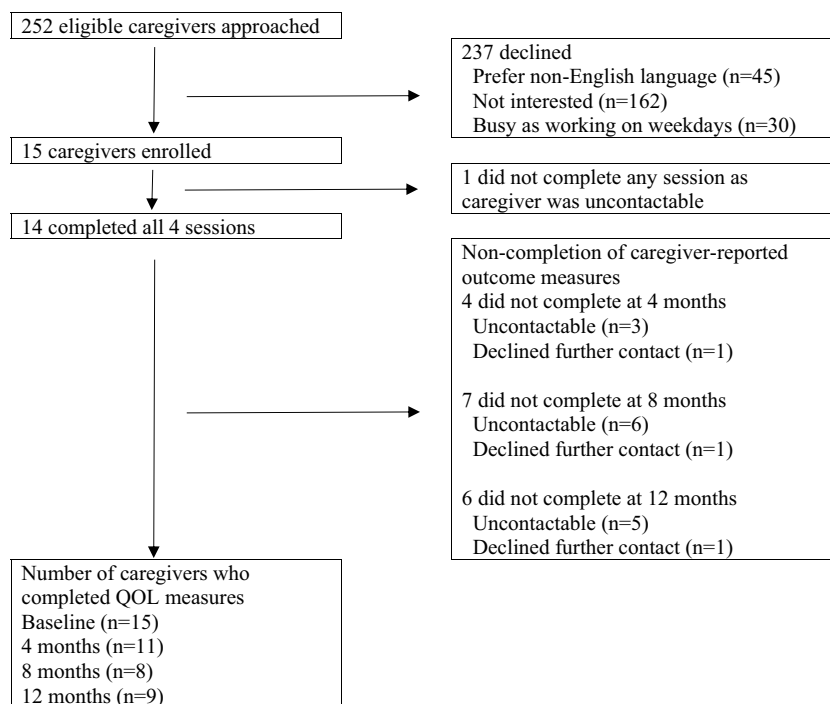**Figure 2.** Study flow diagram for patients.

Figure 3. Study flow diagram for caregivers.

Life Scale, comprising physical, mental, experience and meaning, daily life and financial subscales; score range 0–100, where higher scores indicate better quality of life (Cheung et al. 2019, 2020).

Data analysis

Feasibility of the adapted ENABLE-SG model was measured by the percentage of those eligible who agreed to participate and the percentage of enrolled participants who completed all sessions. A completion rate of 80% and above was considered as evidence for feasibility. Feasibility was considered separately for patients and caregivers. We planned to recruit 30 patients and 30 caregivers for this pilot study. Assuming that the true completion rate was 80%, then a sample size of 30 would give a precision level (width of 95% confidence interval) of about ±15%. Descriptive statistics in the form of frequencies and percentages were computed and tabulated; paired *t*-test was used to compare outcomes at baseline versus 4, 8, and 12 months after enrolment. All analyses were done using the R statistical package version 4.2.3.

Results

We enrolled 43 patients and 15 caregivers over a 10-month period from August 2021 to June 2022. There were challenges in recruiting caregivers due to COVID-19-related restrictions which meant that many patients attending outpatient clinics were unaccompanied by family caregivers. The available resources were therefore used to recruit more patients.

The study flow diagram is shown in Figure 2 for patients. A total of 537 patients were approached, of which 208 (39%) declined as they preferred a non-English language. Of the remaining 329 patients approached, 43 (13%) agreed to participate. Of the 43 patients enrolled, 31 (72%) completed all sessions: reasons for dropping out included rejection by family for patient to participate ($n = 6$), functional decline ($n = 2$), and death ($n = 4$). Patients who completed all 6 sessions did so within a mean of 70.8 days (range 35–152 days), with 84% (26 of 31) patients completing all sessions within 3 months. For patient-reported outcome measures, the completion rate across 4, 8, and 12 months ranged from 56% to 63%. Patient-reported outcome measures at 4, 8, and 12 months were collected via telephone: patients were deemed uncontactable if the phone call was not picked up after at least 3 attempts were made per week for at least 2 weeks.

The study flow diagram is shown in Figure 3 for caregivers. A total of 252 caregivers were approached, of which 45 (18%) declined as they preferred a non-English language. Of the remaining 207 caregivers approached, 15 (7%) agreed to participate. Of the 15 caregivers enrolled, 14 (94%) completed all sessions. Caregivers who completed all 4 sessions did so within a mean of 36.5 days (range 17–95 days). For caregiver-reported outcome measures, the completion rate across 4, 8, and 12 months ranged from 53% to 73%. Caregiver-reported outcome measures at 4, 8, and 12 months were collected via telephone: caregivers were deemed uncontactable if the phone call was not picked up after at least 3 attempts were made per week for at least 2 weeks.

Demographic and clinical characteristics are shown in Tables 1 and 2. Among the 43 patient participants, 65.1% were female and 90.7% had at least secondary school level of education. Among the caregiver participants, 93.3% were female and all had at least secondary school level of education.

For patient participants, there were no changes in any of the FACIT-Pal subscale or total scores over time (Table 3). Although there were 41 participants who met the CES-D threshold score of

Table 1. Characteristics of patient participants ($n = 43$)

	Frequency (%)
Age, mean (SD)	59.1 (13.1)
Gender	
Male	15 (34.9)
Female	28 (65.1)
Race	
Chinese	24 (55.8)
Malay	9 (20.9)
Indian	6 (14.0)
Others	4 (9.3)
Education level	
Primary school	4 (9.3)
Secondary school/ITE	14 (32.6)
Post-secondary level	25 (58.1)
Marital status	
Married	30 (69.8)
Single	8 (18.6)
Divorced/Separated/Widowed	5 (11.6)
Primary site of cancer	
Breast	11 (25.6)
Gynecological	4 (9.3)
Colorectal	12 (27.9)
Upper gastrointestinal	6 (14.0)
Prostate	5 (11.6)
Kidney	3 (7.0)
Lung	2 (4.7)

15 or higher which is interpreted as being as risk for depression, there were no changes in the CES-D score over time.

For caregiver participants, better mental well-being scores were observed at 4 and 12 months; better experience-meaning subscale and total score were observed at 12 months (Table 4). There were no significant differences at 8 months and in the other subscale scores at 4 and 12 months.

Discussion

Although there was a low approach-to-participation rate, most of those who enrolled completed all ENABLE-SG sessions – 72% for patients and 94% for caregivers. Our 56–63% completion rate of patient-reported outcome measures was slightly lower than the 60–75% at 4 months but higher than the 30% completion rate at 12 months reported by other clinical trials of early palliative care among patients with advanced cancer (Bakitas et al. 2015; Temel et al. 2010; Zimmermann et al. 2014). Even though this pilot study was not powered to detect changes in quality of life, we found that caregivers had better quality of life over time, specifically in the subscales of mental well-being and experience-meaning.

The findings from this pilot trial inform future studies in the following ways: A total of 39% of patients approached declined participation as they preferred a non-English language. Even though majority of the Singapore population is bilingual with

Table 2. Characteristics of caregiver participants

	Frequency (%)
Age, mean (SD)	48.0 (13.0)
Gender	
Male	1 (6.7)
Female	14 (93.3)
Race	
Chinese	13 (86.7)
Malay	1 (6.7)
Indian	1 (6.7)
Others	0 (0.0)
Education level	
Primary school	0 (0.0)
Secondary school/ITE	1 (6.7)
Post-secondary level	14 (93.3)
Marital status	
Married	
Single	
Divorced/ Separated/ Widowed	
Caregiver relationship to patient	
Spouse	8 (53.3)
Child	7 (46.7)
Caregiver living with patient	12 (80.0)
Caregiver role	
Physically provide care to patient	8 (53.3)
Ensure provision of care, e.g. supervised paid caregiver	6 (40.0)
Make decision about treatments	6 (40.0)
Pay for medical and health-care expenses	3 (20.0)
Provide psychological/emotional support	12 (80.0)

over 82% literate in English, English was the language most frequently spoken at home for only 48% of the population (Department of Statistics, Ministry of Trade & Industry, Republic of Singapore 2010). For subsequent evaluation and implementation in routine clinical practice, ENABLE-SG should also be available in Mandarin Chinese – the language most frequently spoken at home for 30% of the population, and Malay – the language most frequently spoken at home for 10% of the population.

Given that 6 of the 43 enrolled patients dropped out due to family rejection, efforts should be made to explain the study intervention to family even if the intervention is directed at the patient. This is not surprising in our local Asian culture where families are often very involved in health-care decision-making (Chong et al. 2015; Malhotra et al. 2020; Yang et al. 2012). Future modification may also include the option of family sitting in for the ENABLE-SG sessions with patients. This may reassure family who wish to protect their loved one from unnecessary exposure to "negative" thoughts; however, the family's presence may also steer discussions away from prognostic awareness which is believed to worsen patient quality of life and mood (Satija et al. 2022; Wynn Mon et al. 2021).

Table 3. Quality of life and depression of patient participants

	Baseline (n = 43)	4 months (n = 27)			8 months (n = 24)			12 months (n = 24)		
	Mean (SD)	Mean (SD)	Effect size	p-value	Mean (SD)	Effect size	p-value	Mean (SD)	Effect size	p-value
Physical well-being	20.9 (5.6)	21.8 (6.4)	0.05	0.74	21 (6.6)	0.08	0.65	22.1 (6.2)	0.21	0.34
Social well-being	21 (5.6)	22.4 (4)	0.08	0.51	21.9 (5.4)	0.05	0.72	21.1 (4.8)	0.07	0.65
Emotional well-being	17.3 (5.2)	18.7 (5.2)	0.05	0.55	18.9 (5)	0.08	0.38	18.5 (5)	0.07	0.59
Functional well-being	18.3 (5.5)	19.8 (5.6)	0.1	0.48	20.1 (6.3)	0.04	0.82	18.5 (5.3)	0.13	0.55
Palliative (PalS)	58.8 (9.6)	62.4 (8.4)	0.2	0.28	62.9 (9.1)	0.24	0.2	60.6 (9.3)	0.09	0.66
FACIT-Pal TOI	98 (18.3)	104 (17.8)	0.14	0.33	104 (17.8)	0.11	0.49	101.3 (19.2)	0.07	0.72
FACT-G total score	77.5 (16.1)	82.6 (16.2)	0.09	0.42	81.9 (16.9)	0.03	0.84	80.2 (17.4)	0.03	0.85
FACIT-PAL total score	136.2 (24.6)	145 (23.3)	0.14	0.3	144.8 (24.5)	0.11	0.46	140.8 (26)	0.05	0.76
CESD-R	21.2 (6.4)	20.5 (5.8)	0.1	0.54	19.4 (4.8)	0.12	0.5	20.3 (7.6)	0.01	0.95

Table 4. Quality of life of caregiver participants

	Baseline (*n* = 15)	4 months (*n* = 11)			8 months (*n* = 8)			12 months (*n* = 8)		
	Mean (SD)	Mean (SD)	Effect size	*p*-value	Mean (SD)	Effect size	*p*-value	Mean (SD)	Effect size	*p*-value
Physical well-being	82.5 (11.8)	84.8 (13.8)	0.21	0.22	77.1 (22)	0.14	0.52	88 (20.2)	0.19	0.37
Mental well-being	76.7 (20.3)	81.8 (20.3)	**0.4***	**<0.01**	72 (25.8)	0.14	0.63	87.2 (13.6)	**0.86***	**0.03**
Experience-meaning	65.4 (18.2)	70.1 (24.8)	0.09	0.78	74 (16.5)	0.24	0.14	70.6 (14.9)	**0.41***	**0.01**
Daily life	77.3 (16.8)	83 (16.9)	0.26	0.30	81 (16.1)	0.35	0.47	82.9 (25)	0.41	0.16
financial well-being	73.3 (30.4)	88.1 (14.6)	0.57	0.06	81.2 (20.6)	0.23	0.54	89.1 (16.6)	0.63	0.17
Total	75.3 (11.6)	80.6 (12.8)	0.32	0.06	76.7 (12.5)	0.11	0.71	82.5 (14.5)	**0.65***	**0.03**

* *p* < 0.05

With regard to planning a larger scale trial to evaluate the effectiveness of ENABLE-SG on patient outcomes, the sample size should adequately account for the substantial non-completion rate of patient-reported outcome measures at follow-up time points. Some of the missing data for outcome measures were due to patients or caregivers being uncontactable; study-related processes could be examined to increase the completion rate, for example by allowing for alternative means of contacting study participants. At 12 months, 9 of the 43 enrolled patients (21%) had died, consistent with the advanced stage of cancer in the study population. Study procedures should therefore make provisions for functional decline and even death in at least some of the enrolled patients. There could be flexibility in the content and mode of delivery of sessions, depending on the patient's evolving clinical status; caregiver sessions could include optional bereavement support to be provided if appropriate.

While this pilot study was not designed to assess the effectiveness of ENABLE-SG, it may give a tentative estimate of benefit to inform planning of the subsequent larger scale trial. Compared to baseline, patient quality of life as measured by FACIT-Pal and mood as measured by CES-D did not change significantly at 4, 8, and 12 months. However, there is no comparison group as this single-arm trial did not include a control group who received usual care alone. Other studies have shown that quality of life for patients with advanced cancer usually has a downward trajectory in the last months of life (Kristensen et al. 2022; Shafiq et al. 2022). In light of this, it is possible that the ENABLE-SG intervention could have prevented the otherwise natural decrease in quality of life – this could be explored in future studies.

Caregivers who participated in the ENABLE-SG sessions had better mental well-being at 4 and 12 months, and better experience-meaning at 12 months. This is a promising finding that could be assessed further in a subsequent larger scale trial. Although originally designed as a dyadic intervention, caregivers in this pilot study participated without a dyadic patient. Whether or not there is differential benefit for dyadic versus non-dyadic participation could also be explored further.

Limitations

Our study had limitations. The ENABLE-SG sessions were conducted only in English, leading to a high nonparticipation rate due to preference for non-English language. At this pilot stage, our intention was to establish feasibility in English before translating to Mandarin Chinese and Malay for further evaluation and subsequent implementation. Due to COVID-19-related restrictions, we were not able to recruit the planned number of caregivers;

these restrictions have now been lifted and the effectiveness of ENABLE-SG for caregiver outcomes could hopefully be more comprehensively evaluated in a subsequent study. There was a high non-completion rate for patient- and caregiver-reported outcomes; this will be accounted for in the planning of follow-up trials.

Conclusion

Despite the low approach-to-participation rate, 72% of patients and 94% of caregivers completed all ENABLE-SG sessions. Although the 72% completion rate for patients did not reach the 80% completion rate that was set a priori, it is close enough for us to consider the ENABLE-SG intervention feasible. Further modifications will be done to increase the completion rate: for example, eligibility criteria for patients could be modified to exclude patients who are later in the disease course so as to reduce incompletion due to clinical deterioration. There was also some indication of benefit in quality of life for caregivers. Based on findings from this study, we are planning a randomized waitlist-controlled trial of ENABLE-SG for patients with advanced cancer and their caregivers.

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