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## Effects of a nurse-led advance care planning programme for community-dwelling patients nearing the end of lifewith serious illnesses and their family members: A randomised controlled trial

### Abstract

*Background:* Despite increasing evidence of the effects of advance care planning, the quality of the relevant studies is questionable, and consensus is lacking regarding “whom to” and “when to” initiate the conversation.

*Objective:* To examine the effects of a nurse-led advance care planning programme on concordance between patient and the nominated family member in end-of-life care preferences, decisional conflictthe level of certainty in decision-making and documentation of care preferences. among community-dwelling patients with serious illnesses.

*Design:* A two-arm parallel-group randomised controlled trial.

*Participants:* A total of 230 dyads comprising community-dwelling patients screened by the Gold Standards Framework Prognostic Indicator Guidance with serious illnesses and their nominated family members.

*Methods:* The experimental group participated in a structured advance care planning programme administered by a trained nurse during three weekly home visits. The control group received home visits focused on self-care management. The study outcomes were dyadic concordance regarding the end-of-life care preferences, patients’ level of decisional conflict the level of certainty in end-of-life decision-making and documentation of these preferences at baseline and 1 and 6 months after enrolment. The Pearson chi-square test and independent t-test were used respectively to compare categorical and continuous variables between the two groups. A repeated measures analysis of variance was used to compare mean scores over time.

*Results:* At baseline, few participants had ever heard of advance directives (2.6%) and or few patients had ever discussed end-of-life issues with family membersothers (14.8%). During the study, 35 patients died, 15 patients become very ill, 17 patients or family members withdrew from the study and 12 were lost to follow up. Although no significant inter-group differences were observed in terms of the end-of-life care preferences and level of certainty in decision making, the mean scores of the experimental group improved significantly over time. Notably, the experimental group had significantly higher rates of completion of advance directives and documentation of do-not-attempt cardiopulmonary resuscitation orders in the electronic medical records than the control group.

*Conclusions:* This study revealed a poor level of awareness regarding advance care planning among patients with end-of-life conditionswith serious illnesses and showed that a nurse-led structured advance care planning programme could effectively increase patients’ level of certainty regarding the decision-making process and documentation of care preferences. The study also underscoredhighlighted the importance of introducing the planning process at an earlier time to allow patients sufficient time to contemplate end-of-life issues, empowering them to deliberate on their choices by increasing their health

literacy regarding various care and treatment options and engaging them in open discussion by providing additional nursing manpower and time to support advance care planning.

**Keywords:** Advance care planning; End-of-life care; Decision-making; Communication; Nurse; Patient empowerment

### **What is already known about the topic?**

- Patients nearing the end of life~~with serious illnesses~~ were poorly prepared to make informed end-of-life care decisions.
- Preferably, advance care planning should be initiated by non-physician health professionals.
- Previously published findings regarding the effects of advance care planning for eliciting end-of-life care preferences and reducing decisional conflicts are inconsistent.

### **What this paper adds**

- This study demonstrates that designating a trained nurse as a facilitator to engage patients in advance care planning can effectively improve patient confidence in end-of-life decision-making.
- The study findings suggest that providing written information about and regular assessments of end-of-life care preferences may encourage patients to contemplate these issues.
- Furthermore, it underscorehighlights the importance of providing additional nursing manpower and time to support the implementation of advance care planning.

## **1. Introduction**

### *1.1 Background*

Advance care planning is defined as a process by which individuals are encouraged to clarify their personal values regarding future medical care, discuss their preferred care goals and preferences in ~~serious illness~~end-of-life -related scenarios with their family members and health care team and document these preferences before they lose their decisional capacity (Rietjens et al., 2017; Sudore et al., 2017). Primarily, advance care planning aims to improve ~~congruence~~concordance between an individual's end-of-life care preferences and the actual care received (Houben et al., 2014; McMahan et al., 2013). Existing recommendations widely advocate the integration of advance care planning into the care provided to all people with chronic progressive diseases (i.e., not limited to cancer diagnoses) (The National Council for Palliative Care, 2008).

### *1.2 Quality of evidence*

Advance care planning is a complex intervention that encompasses various interacting components and dimensions that may be influenced by the attitudes and behaviours of those who deliver or receive the intervention (Gilisen et al., 2017; Medical Research

Council, 2008). This nature has led to increasing interest in identifying the active ingredients and mechanisms associated with advance care planning with the intent of enhancing its effectiveness and sustainability. Several systematic reviews have noted the low level of quality of many relevant studies (Brinkman-Stoppenlenburg et al., 2014; Houben et al., 2014; Oozkowski et al., 2016; Ng et al., 2016; Robinson et al., 2011), particularly with regard to major limitations such as a lack of random allocation; a lack of blinding among patients, facilitator/interventionists and assessors; small sample size; lack of description of the strategies implemented to ensure implementation fidelity and the use of inappropriate data analysis methods. These limitations have raised concerns that compromised internal validity might result in an overestimation of clinical efficacy.

Apart from these methodological issues, most studies have been disease-specific and conducted in institutionalised settings such as hospitals and nursing homes (Brinkman-Stoppenlenburg et al., 2014; Newbould et al., 2012). Moreover, the outcomes of these studies mainly involved the completion of advance directives (Brinkman-Stoppenlenburg et al., 2014; Houben et al., 2014), and the reported effects of advance care planning on eliciting end-of-life care preferences and reducing decisional conflicts were inconsistent (Houben et al., 2014).

### *1.3 Advance care planning facilitators*

Previous reports have consistently noted that advance care planning should be conducted by health care professionals with necessary skills and knowledge. However, these studies lack consensus regarding the party responsible for conducting advance care planning (Gilissen et al., 2017), and this lack of clarity in terms of the responsibilities of generalists and specialists for the initiation of advance care planning have hindered the process (Izumi, 2017; Ke et al., 2015). Recent studies found that both patients and health care professionals perceived non-physicians to be more tactful skilful when discussing in broaching end-of-life care issues-advance care planning (Arnett et al., 2016; Clark et al., 2015; Scott et al., 2016). Likewise, a Delphi consensus process involving an international expert panel yielded a high level of agreement with the initiation of advance care planning by a non-physician (Rietjens et al. 2017). Izumi (2017) argued that nurses are well positioned to initiate advance care planning because they experience more frequent and regular contact with patients and family members and often act as the hub in multidisciplinary teams. Ke et al. (2015) also identified that the various roles held by nurses, which include educator, assessor, communicator, advocator and case manager, facilitate advance care planning.

This study aimed to examine the effects of a nurse-led, structured advance care planning programme on end-of-life care decision making for patients nearing the end of life-with serious illnesses. We hypothesised that a significantly higher proportion of participants in the experimental group would be able to state their end-of-life care preferences with a higher level of certainty in their decision-making and documentation of care preferences, compared with the control group.

### *1.4 Conceptual framework of the nurse-led advance care planning programme*

The advance care planning programme applied in this study was modified from the Let Me Talk programme developed for nursing home residents, which uses a narrative approach (Chan and Pang, 2010). The programme was modified to be more succinct while addressing three aspects (Figure 1). In first part of the programme, My Stories, individuals were encouraged to share their experience of illness. In the second part, My Views, individuals reflected upon their personal values and beliefs as based on their life experiences. McMahan et al. (2013) also noted in a qualitative study of the sharing of patients and surrogates who involved in end-of-life decision making that advance care planning should not only focused on specific treatment. Rather, it was expected to provide an avenue by which individuals could identify values stemming from past experiences. In the third part, My Wishes, individuals navigated various issues concerning end-of-life care, provided information and clarified their individual preferences regarding the goals of care and treatment. During this part, the nurse also assessed the individual's readiness for an in-depth conversation about end-of-life care issues (Chan and Pang, 2011). The nurse was provided with the flexibility to tailor the conversation and adjust the flow of discussion according to the patient's pace. In line with the recommended approach for advance care planning (Rietjens et al., 2017), the overall design of this programme adopted a person-centred approach to engage individuals in advance care planning. Nurses were able to explore the patient's emerging concerns and worries related to the illness in an individualised context. Repeated encounters enabled the nurse to build rapport with patients and their family members and understand the unique situation of each individual. Family members were encouraged to remain present so that consensus could be achieved via facilitated discussions.

## 2. Methods

### 2.1 Study design

This parallel-group randomised controlled trial with repeated-measures was conducted between March 2014 and February 2016. Patients were recruited from eight medical wards and an outpatient clinic of a 425-bed rehabilitation-oriented hospital in Hong Kong.

### 2.2 Sample

We recruited The target participants were dyads comprising a patients and their nominated family members in dyad format to the study because one of the major purposes of advance care planning is to improve communication between patient and their family members regarding end-of-life care. Patients were considered eligible for the study if they met one of the three triggers for supportive care suggested in tThe Gold Standards Framework (GSF)Prognostic Indicator Guidance which was developed to support clinicians in early identification of patients nearing the end of life was used as a screening tool in this study (Royal College of General Practitioners, 2011). It comprises three triggers, they are affirmative answer to the "Surprise Question" regarding prognostication in the following 12 months; general indicators of health deterioration; and specific disease-specific clinical indicators. The inclusion criteria of patients were: meeting one of the three triggers in the screening tool, were at least 18 years of age, were mentally

competent, could communicate in Cantonese and lived at home. Patients who were eligible to the study and interested in the study were invited to nominate a family member who would involve in their end-of-life decision making. Patients were excluded if they could not nominate a family member to join the study, had been referred for palliative care service or had completed an advance directive before the study. Nominated family members were invited to participate in the study if they were at least 18 years of age and had had at least one contact with the patient in the past 3 months.

Based on previous feasibility studies (Chan and Pang, 2010; Chan et al., 2014), we projected that the 30% and 10% of patients in the experimental and control groups, respectively, would express end-of-life care preferences at the sixth month (i.e., relative risk, 3.0). Therefore, a sample size of 72 patients in each arm would be needed to achieve a power of 80% to detect a 20% difference between groups, using a two-sided chi-square test at a 5% level of significance. Assuming an attrition rate of 35%, approximately 220 patients would be recruited to yield 110 patients per arm.

### *2.3 Intervention*

After hospital discharge, the advance care planning programme was administered by a trained nurse during three weekly home visits conducted in the presence of the nominated family member. The nurse had attended a 4-day end-of-life training programme provided by a professional palliative care society group, which covered symptom management, psychosocial and spiritual care, grief and bereavement, communication and counselling and self-care. The principal investigator, who was experienced in advance care planning, also accompanied the nurse during delivery of the intervention to the first five patients and subsequently provided coaching and feedback. Thereafter, the principal investigator also randomly joined the interventions administered to 20 patients as a participant observer and thus monitored intervention adherence.

At the end of the first meeting, the participants were provided with an educational leaflet about advance care planning. At the end of the programme, the nurse summarised and documented the discussion regarding advance care planning discussion in a personal workbook for record, and also explained the content of the advance directive form which is publicly available on the internet. If the patient wished to sign an advance directive, the nurse ~~also~~ arranged an outpatient appointment in which a medical doctor could serve as a witness.

### *2.4 Usual care Attention control*

Two weekly home visits which mimics the inactive components in the intervention were arranged for patients in the control group to reduce ascertainment bias ensure that the participants remained blind to their group assignment. The purpose of these visits was similar to those associated with other discharge programmes; that is, the nurse performed basic health assessments and medication reviews. The nominated family member was also encouraged to be present during the home visits. ~~The patients in the control group also received a~~ The leaflet about advance care planning which was given to the experimental group was also given to the participants in the control group at the end of the first home

visit for self-perusal. The nurse was not proactive in explaining the content in the leaflet or clarifying their relevant values. If the participants seek assistance in completing an advance directive, the nurse provided the form for their reference and advised them to further talk to their medical doctors.

## 2.5 Study outcomes

The primary study outcome was the congruence between whether the patients could state his or her patients' end-of-life care preferences and those predicted by the nominated family member. The secondary outcomes were the patient's decisional conflict level of certainty regarding about end-of-life decision-making and the presence of documentation of the end-of-life care preferences in medical records. The outcome measures were evaluated at the baseline (T0) and at 1 (T1) and 6 months (T2) after enrolment. The participants' demographic data and the patient's health conditions (e.g., diagnoses) were collected at baseline. The Life-Support Preferences Questionnaire (Ditto et al., 2001) was modified to evaluate the end-of-life care preferences. Specifically, the questionnaire was simplified to assess preferences regarding (i) three kinds of life-sustaining treatments (cardiopulmonary resuscitation, mechanical ventilator and tube feeding) based on three options (want to attempt, refuse or uncertain) and (ii) care goals (comfort-oriented, prolongation of life at all costs or uncertain) regarding two hypothetical end-of-life scenarios (terminally ill and in a persistent vegetative state ~~[PVS]~~ or irreversible coma). These scenarios were based on the local advance directive form. Both the patient and the nominated family members completed this questionnaire individually and simultaneously. The dyadic concordance in end-of-life care preferences was determined based on the extent of agreement between the patient and the nominated family member regarding specific treatment refusal and choosing comfort care as the goal of end-of-life care. The 4-~~item~~ SURE test, which was a brief and validated tool developed based on the Ottawa Decision Support Framework~~addresses self-efficacy, understanding of the potential risks or benefit of the respective treatment options and information support,~~ was used to measure the patient's level of decisional conflict the level of certainty regarding end-of-life decision-making (Legare et al., 2010). It comprised four items about self-efficacy, information understanding, risk-benefit ratio and information support, with a dichotomous response format (1 = Yes and 0 = No). For this test, each affirmative answer received 1 point, and a higher summed score indicated a higher level of certainty regarding decision-making. Good construct validity and reliability of the SURE test were demonstrated. The documentation of patients' ~~documented~~ end-of-life care preferences were retrieved from the electronic medical records six months after enrolment. The documentation could be in the format of ~~included~~ the completion of an advance directive and the presence of decisions regarding specified life-sustaining treatments in end-of-life situations (e.g., Do Not Attempt Cardiopulmonary Resuscitation ~~[DNACPR]~~) entered by the medical doctors into the electronic records.

## 2.6 Procedure and ethical considerations



Ethical approval for this trial was obtained from the Cluster Research Ethics Committee of the Hospital Authority. Two medical doctors initially screened patients ~~for eligibility~~ and referred potential participants to a research nurse for subject recruitment. The research nurse approached the patients and the nominated family member individually to confirm their eligibility and explain the nature and purpose of the study. -If the patient-family member dyad agreed to participate in the study, written informed consent were obtained from both of them. The participants were assured of their right to withdraw from the study at any time without reprisal. ~~Interested patients nominated a family member to participate in the study as a dyad.~~ The dyads were randomly assigned to either the control group or the experimental group using sealed opaque envelopes with randomly generated numbers, which were prepared by a statistician who was not involved in the subject recruitment procedure. The allocation was concealed from the ~~participants and~~ assessors during follow-up assessments. All follow-up assessments were conducted during face-to-face meetings by two nurses who were blinded to the group allocation. Training was provided to ensure inter-rater reliability.

### 2.8 Data analysis

The statistical analyses were performed using the Statistical Package for the Social Sciences (SPSS), version 24.0 (IBM Corp., Armonk, NY). Descriptive statistics were used to summarise the participants' characteristics, outcomes and attrition rate. The effectiveness of the intervention was evaluated by comparing the study outcomes between the experimental and control groups. The Pearson chi-square test and independent *t* test were used respectively to compare categorical and continuous variables between the two groups. A repeated measures analysis of variance was used to compare the mean SURE test scores across the three time points. Levene's test for homogeneity of variances (significance level  $< .05$ ) was used to ~~assume~~ ensure the homogeneity of variance in the test scores. All analyses were two-sided and performed on an intention-to-treat (ITT) basis such that all randomised subjects were included in the analyses to enhance the validity of the study findings. ~~A last observation carried forward (LOCF) method was used to address missing values in the follow-up assessment. This conservative estimation method assumes no changes in care preferences over time.~~ A *p* value of less than .05 was considered to indicate statistical significance.

## 3. Results

### 3.1 Participants' characteristics

A total of 337 eligible patients were approached for this study. Among them, 239 patient-family dyads agreed to participate, yielding a participation rate of 70.9% (Figure 2). The major reasons for non-participation were a lack of interest in the topic, fatigue, inability to identify a family member to participate in the study or lack of family support for study participation. After nine patients became critically ill or died before group assignment, 230 dyads were ultimately included in the study. As shown in Table 1, the patients had a mean age of 77.7 years (SD 9.1), and approximately two-thirds were male. Most patients lived with family members. The major diagnoses were chronic respiratory

diseases (52.7%), heart diseases (19.2%), stroke (5.9%) and cancer (5.4%). The family participants had a mean age of 57.8 years (SD, 14.3); most were female and nearly half were the patient's spouse. The demographic characteristics and health conditions of the participants at baseline did not differ significantly between the two groups except in terms of the marital status of the family participants.

During the study, 79 dyads (34.3%; 44 in the experimental group and 35 in the control group) were lost to follow-up (Figure 2). Of them, 35 patients died, 15 patients became very ill, 17 patients or family members withdrew from the study because they were uncomfortable with discussing death and related issues and 12 remained inaccessible despite multiple attempts. The baseline characteristics and group assignments did not differ significantly between the study completers and non-completers.

### 3.2 *Dyadic concordance in End-of-life care preferences*

At T0, few participants had previously heard of advance directives (12/460; 2.6%) and ~~or few patients~~ had discussed end-of-life care issues with ~~others-family members~~ (34/230; 14.8%). Table 2 presents the patients' treatment preferences and goals of care for the two specified end-of-life scenarios. The experimental and control groups only differed significantly in their preference for receiving tube feeding in case of PVS or irreversible coma at T2.

### 3.3 *Level of certainty/Decisional conflict in end-of-life decision-making*

Table 3 demonstrates that the mean SURE test scores did not differ significantly between the two groups at the three time points. However, a comparison of the scores across the three assessment time points revealed a significant interaction between group and time (Wilks' Lambda = .96,  $F(2, 227) = 4.81$ ,  $p = .009$ ), indicating that the intervention effect differed between the two groups. In a separate examination of each group, this effect was only found to be statistically significant in the experimental group (Wilks' Lambda = .85,  $F(2, 113) = 10.31$ ,  $p \leq .001$ , multivariate partial eta squared = .15). Post hoc comparisons (Bonferroni test) demonstrated significant differences of the mean score at T0 from those at T1 and T2 in the experimental group.

### 3.4 *Documentation of end-of-life care preferences*

At six months, ~~the rates of~~ completion rate of advance directives in electronic medical records was significantly higher in the experimental group than in the control group (16.5% vs. 1.7%,  $p \leq .001$ ). Likewise, ~~and the~~ documentation of the Do Not Attempt Cardiopulmonary Resuscitation DNACPR order in the experimental group was also significantly higher than that of the control group in electronic medical records were significantly higher in the experimental group than in the control group (advance directives: 1.7% vs. 16.5%,  $p \leq .001$ ; DNACPR: ~~17.40%~~ vs. ~~17.40%~~,  $p = .016$ ). No records of the patients' preferences regarding other life-sustaining treatments were found.

## 4. Discussion



This randomised controlled trial provides empirical evidence of the effects of a nurse-led structured advance care planning programme for patients nearing the end of life with serious illnesses. Subject recruitment was conducted in medical wards with the aim of recruiting non-cancer patients, who are considered an under-researched group in advance care planning studies (Newbould et al., 2012). As demonstrated by the baseline data, the participants' awareness of the need to plan and discuss end-of-life care issues was generally poor. Despite the advanced stages of the patients' medical conditions (15.2% died and 6.5% become mentally incapacitated during the study period), a considerable proportion of participants remained indecisive about end-of-life care, consistent with Izumi's (2017) observations that patients with poor prognoses and their family members were often unprepared by previous end-of-life care discussions. In a study of current practices, Newbould et al. (2012) also found that advance care planning for people with long-term conditions was often conducted on a reactive basis.

Here, we sought to examine the effects of advance care planning in a real setting, which includes the potential influence of family members. Accordingly, we required patients and their family members to participate as dyads in the study. This requirement might have increased the challenges associated with recruitment and would thus explain the lower participation rate and higher attrition rate in this study relative to other studies (Brinkman-Stoppenlenburg et al., 2014; Houben et al., 2014; Oczkowski et al., 2016; Robinson et al., 2011; Ng et al., 2016). For instance, some patients were unable to participate in the study because of family objections. During the advance care planning process, some family members became upset with the discussion, imposed their views upon the patients or prohibited them from expressing their views. In addition, we were unable to reach some patients directly for follow-up assessments because of family refusals to participate. It is therefore difficult to ascertain whether the patients themselves did not want to discuss the issue and asked their family members to refuse out of courtesy or whether the family members did not allow the patients to reconsider the issue.

We further note that more male than female participants were included in this study. This gender imbalance among participants was consistent with an earlier study by Walczak et al. (2017). Perhaps the male patients were likely more accustomed to exerting control over their lives, including medical care, whereas female patients were relatively more submissive to decisions made by their family members. However, Skulason et al. (2014) showed that male patients were less willing to engage in emotionally difficult conversations and thus more reluctant to discuss end-of-life issues than their female counterparts.

Compared with the control group, a significantly higher proportion of participants in the experimental group had an DNACPR-order of not attempting cardiopulmonary resuscitation in their medical records or had completed advance directives. These results were congruent with previous studies in which advance care planning was found to promote the formal documentation of end-of-life care preferences (Houbens et al., 2014; Oczkowski et al., 2016). However, the level of certainty regarding end-of-life decision making did not significantly differ between the experimental group and control group in any of our three study time points. This lack of significant group differences in the level

of certainty, treatment preferences and care goals at the three time points is noteworthy. The proportion of participants in the control group who remained indecisive also largely decreased over time, which closed the gap between the two groups. Likewise, Song et al. (2010) also noted a reduction in decisional conflicts over time in patients in both the experimental and control groups, with a corresponding lack of significant group differences. These changes might be attributable to the use of assessment questions intended to elicit care preferences or the provision of educational leaflets that also prompted participants in the control group to contemplate end-of-life care issues. Nevertheless, the mean score in the experimental group increased significantly from T0 to T1 and remained elevated at T2, whereas changes within the control group were not significant. These results might emphasise the importance of an advance care planning facilitator, as the level of certainty regarding treatment decisions did not improve significantly in the control group in the absence of a professional to guide the process and provide information support.

This study had several limitations that should be acknowledged. First, we could not avoid participation bias, because the voluntary participants may have been more receptive towards the concept of advance care planning than those who chose not to participate. Second, this study was conducted in a hospital with a more supportive culture regarding the concept of advance care planning, which may influence the generalisability of our findings to other hospitals. Third, we could not ascertain whether the family members nominated by the patients to participate in the study would have had the final say regarding the patients' end-of-life care decisions.

Notwithstanding these limitations, this study contributes to the field by providing major implications for research and practice at both the organisational and societal levels. It also highlights the importance of the early engagement of patients with chronic progressive diseases in advance care planning. Although the difficulties with prognostication in this patient group has often been considered an obstacle toward determining the best timing for introduction of advance care planning (Billing and Bernacki, 2014), the high risks of mortality and morbidity revealed in this study demonstrate that these patients should be better prepared for the anticipated health changes and treatment decisions at an earlier stage in their illness trajectory. The integration of a structured advance care planning programme into primary care services would thus support a consistent and systematic approach that would provide all patients with sufficient time to contemplate end-of-life care issues. Accordingly, it is imperative to increase patients' health literacy regarding various treatment options associated with end-of-life care and thus empower them in the decision-making process. In addition to information support, this study further underscore highlights the importance of a facilitator who can engage patients and family members in advance care planning by building patients' confidence in their treatment decisions and bridging the communication gap between patients and their families. One major advance in this regard will be the provision of sufficient nursing manpower and time to support the implementation of highly individualised process of advance care planning and thus address the complex care needs of patients nearing the end of life-with serious illness. To this end, Travers and

Taylor (2016) recommended a board-level commitment at the organizational level to supporting the delivery of advance care planning. Further research regarding the factors that influence a willingness to participate in advance care planning, including gender, educational level, health conditions and family relationships, is warranted. Longitudinal studies are also needed to examine the effects of advance care planning on health care utilisation and the congruence ~~concordance~~ between care preferences and actual end-of-life care.

## Conclusions

This study examined the effects of a nurse-led, structured advance care planning programme for patients nearing the end of life ~~with serious illnesses~~. Notably, this programme appeared to effectively increase the patients' level of certainty regarding the decision-making process and documentation of care preferences. The results of this study also ~~underscore~~ highlight the importance of providing patients with sufficient time to contemplate end-of-life issues by introducing the planning process at an earlier time, as well as the importance of empowering them to deliberate their choices by increasing health literacy towards various care and treatment options and engaging them in open discussion by providing the additional manpower and time for support the implementation of advance care planning.

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