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研究課題名（和文）Do patients make decisions about their end of life care in advance? Impact of Advance Care Planning (ACP) on end-of-life (EoL); comparing practices between UK and Japan

研究課題名（英文）Do patients make decisions about their end of life care in advance? Impact of Advance Care Planning (ACP) on end-of-life (EoL) in ICU; comparing practices between UK and Japan

研究代表者

Anagnostou Desp (Anagnostou, Despoina)

京都大学・医学研究科・准教授

研究者番号：70817684

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研究成果の概要（和文）：集中治療室（ICU）における終末期ケア介入に関するシステマティックレビューによると、ICUに緩和ケアが統合された場合、家族のコミュニケーションとACPの実施に関してより良いアウトカムが認められた。2. 緩和ケアやICUに関連する英国と日本の臨床医へのインタビューから、両国ともICUにおけるACPを重要視しているが、文化的価値観の違いを反映して、焦点の当て方は異なっていることが明らかになった。患者の自律性（英国）対患者の尊厳（日本）患者中心（英国）対家族中心（日本）の意思決定がその違いの一部であった。英国の臨床家は患者の能力を判断することが基本であると考え、日本の臨床家は家族の希望を優先した。

研究成果の学術的意義や社会的意義

これは、アドバンス・ケア・プランニングに関して英国と日本を比較した初めての研究である。レビューの結果、個々のICUの文化、ACPのトレーニング、緩和ケアチームの関与が、それぞれの病棟におけるACPの取り組みと実践のばらつきに影響しているようである。インタビューでは、両国とも患者の苦痛を和らげたいと考えているが、英国の臨床家は「患者の最善の利益」を優先し、日本の臨床家は家族の満足を優先していることが明らかになった。したがって、異なる国でアドバンス・ケア・プランニングを実施する際には、文化的背景と社会の価値観を理解することが重要である。

研究成果の概要（英文）：Two phases: 1. A systematic review in relation to End-of-life care in ICU, with a focus on communication and decision-making across countries. 2. Interviews with clinicians and academics in UK and Japan, to identify attitudes about advanced care planning (ACP) and its use in the intensive care (ICU) context. We generated international evidence, which demonstrated that when palliative care was integrated in the intensive care, better outcomes were found with regards to family communication and decision-making, alongside ACP implementation. The interviews revealed that both countries are considering the importance of ACP in ICU, but gave a different focus, reflecting differences in cultural values. Patient autonomy(UK) vs patient dignity (Japan) and patient-centered (UK) vs family-centered (Japan) decision-making were some of the key differences. Determining patient capacity was perceived fundamental by UK clinicians, whilst family's wishes took priority by JP clinicians.

研究分野：palliative care

キーワード：palliative care advanced care planning Intensive Care decision-making ICU ACP

1. 研究開始当初の背景

End of Life (EoL) preferences of many hospitalized patients at high risk of death remain unclear to both substitute decision-makers (SDMs) and clinicians, and are often undocumented in the medical record, as patients may not understand their care options, or may not document their care preferences in an AD. This may result to unwanted treatments at the EoL, which in turn are associated with poorer quality of life and psychological harm for both patients and families (Wright et al 2008). Studies so far, are inconclusive about whether ACP or ADs are helpful in delivering care that is consistent with patient preferences, improving EoL, or reducing resource utilization (Hartog et al, 2014; Leder et al, 2015; Halpern et al, 2011). Practices of ACP across different countries vary significantly, which might reflect differences in cultural values, established medical practices and legal frameworks. But little comparative work is being done to explore differences between Western and Asian regions or countries (Mark et al, 2015). The debate about the end-of-life care decision is increasingly becoming a serious ethical and legal concern in the Far-Eastern countries (Kwon et al 2015), with recent studies indicating that more patients are willing to participate in ACP practices (Ivo et al 2012).

Within the ICU context, despite a significant development of Advanced Care Planning (ACP) is observed, inadequate ACP support is provided to ICU patients. Variation of implementation across different countries is documented and needs to be understood. Differences in the way ACP is considered in UK and Japan have been reported, with UK prioritising patient-centred care and open/ direct communication, whereas Japan preferring implicit communication, whilst prioritising family harmony. Specifically in Japan, the general public have become increasingly interested in the expression and enhancement of their individual autonomy in medical decisions made at the end of life (Akabayashi et al, 2003). However, when patients were deprived of decisional capacity due to physical, mental and cognitive deterioration, family or relatives were asked to make judgements on treatment choices on behalf of them (Fujimoto et al, 2014).

2. 研究の目的

The aims of this research are: (i) to explore the different perspectives on advanced care planning (ACP) between Japan and UK and (ii) to explore its implementation potential in patient care within the intensive care context particularly.

3. 研究の方法

(1) PHASE I: Systematic review

Systematic review aim: What is the effect of EoL care interventions onto patient/ family and physician outcomes and resource utilisation, across different countries in intensive care?

a. For the protocol development we followed the PRISMA guidelines (PRISMA, 2015). The protocol was

published in PROSPERO, (ID: CRD42018094315).

b. For the conduct of systematic review we followed the Cochrane Systematic review guidelines.

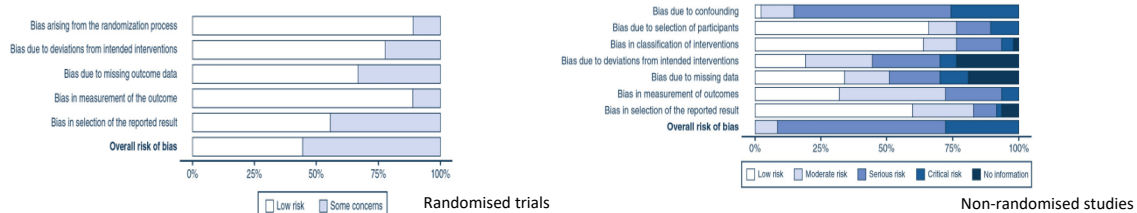
(2) PHASE II: Interview study

Qualitative, semi-structured interviews with ICU and PC health care professionals from the UK and Japan, with clinical and/or academic experience in the field. Interviews were conducted either face-to-face or via zoom, following an interview guide. The guide was developed with a focus on stakeholders' views on patient care management at end of life care in relation to ACP, experiences in implementing ACP, with a focus on hindlers/ facilitators, and their perceptions on how involved patients wish to be in treatment decisions. Purposely sampled physicians and nurses with palliative care or intensive care clinical experience and academics involved in EoL care in both areas, through professional networks. Interviews were audio/video recorded and transcribed verbatim. The data was managed with N-Vivo and analysed using a) thematic analysis to identify facilitators and barriers in ACP implementation, and b) qualitative comparative analysis to identify context specific differences between the two countries.

4. 研究成果

(1) Phase I: systematic review

The systematic review expanded to include all EoL care interventions. We, therefore, collaborated with the European Society of Intensive Care, to produce a bigger systematic review, including international experts in the field. The full study is already published (MetaxaV, Anagnostou D, et al 2021). Nine randomised and 49 cohort studies (mostly pre/post interventions) were included. The methodological quality of the studies varied significantly, with the majority of the non-randomised ones being scored as high or critical risk of bias.



Interventions: were categorised into five themes: communication (24.6%), ethics consultations (8.8%), educational (31.6%), involvement of a palliative care team (49.1%) and advance care planning or goals-of-care discussions (12.3%). Thirty studies (51.7%) proposed an integrative model, whilst 28 (48.3%) reported a consultative one. Advanced care planning was one of the five types of interventions identified and proposed for End of life care in the intensive care context. However, the vast majority of the included studies took place in the United States (51, 87.8%) with 3 (5%) being carried out in France 3 (5%) in Canada and 1 (2%) in the UK. This signifies the importance of prioritising decision about care within which advanced care planning is included.

Outcomes: Reported outcomes were associated with mostly process and output, and less with patient

outcomes (table 3). The most frequently reported outcome measures were ICU/hospital length of stay (34/58, 58.6%), limitation of life-sustaining treatment decisions (22/58, 37.9%) and mortality (15/55, 25.9%). Consultation interventions showed higher impact on ICU and hospital length of stay, whilst the consultative model was associated with a greater number of limitations of life sustaining treatments decisions. Key improvements in outcomes were identified to be: Reduction of ICU length of stay (11/30 studies), Increase of frequency of structured family meetings (6/6 studies), Increase of PC consultations, Increase of DNAR and LST decisions (11/22 studies), Family/ clinician satisfaction (11/13 studies), Decrease of psychosocial distress (4/6 studies).

| Content related | System related | Family/ clinician related |
|-----------------------------------|--------------------------------------|--|
| ICU LoS | ICU mortality | FAMILY |
| Hospital LoS | Hospital mortality | Knowledge of CPR |
| Symptom control documentation | % patients receiving CPR | Family satisfaction |
| Days of mechanical ventilation | % patients with DNAR/WH/WD decisions | (communication, QODD, information provided, decision-making, overall care, presence of a SW) |
| Days of vasopressors | Time to LST limitation decisions | Psychological distress |
| Days of renal replacement therapy | % ACP | CLINICIAN |
| Days of ANH | | Nurse satisfaction (communication, QODD, conflict resolution, support, knowledge) |
| Family meetings | | Physician satisfaction |
| Palliative care consultations | | Psychological distress |
| Discharge to hospice | | |

ACP: Advance care planning; ANH: artificial nutrition and hydration; CPR: cardiopulmonary resuscitation; DNAR: do not attempt resuscitation; ICU: Intensive Care Unit; LoS: length of stay; TISS: therapeutic intervention Scoring System

Table 3:Reported outcomes measured in the studies

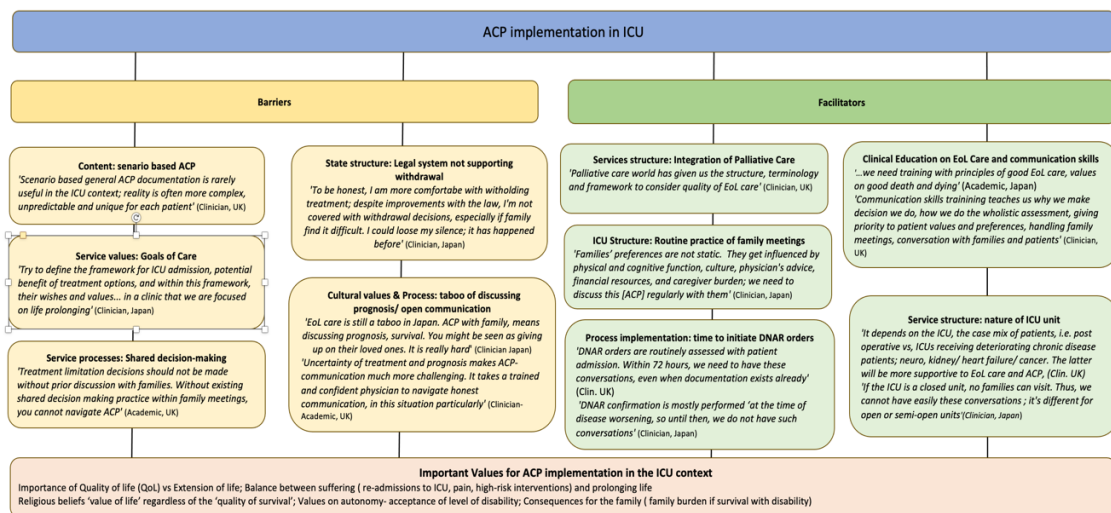
Discussion- Conclusion: Although patient-centered outcomes after ICU are difficult to measure, the lack of data on physical, cognitive, and psychological outcomes of critically ill patients is problematic. The most commonly used outcomes (ICU and hospital LoS) provided limited information with regards to change in patient quality of life or quality of dying and may be difficult to generalise to most countries outside North America. Beneficial effects were associated with active palliative care involvement strategies. A core set of validated outcomes with a patient-centered focus should be prioritized, to allow meaningful comparisons.

(2) Phase II: Interview study

Twenty-five ICU and PC clinicians (13 men and 12 women) with clinical and/or research experience of 3-20 years in ACP or EoL care implementation in palliative care or intensive care context. This phase will generate evidence in relation to current practices, constraints and facilitators of ACP in the two different countries. Withholding and withdrawing of life-sustaining treatment, alongside surrogate decision-making were considered as the main ICU practices relevant to ACP conversations. The UK clinicians highlighted the importance of ACP discussion and documentation for after discharge, regarding future admission of patients with chronic illness, named escalation plan. Barriers were identified in relation to ACP content, process of implementation and service structure. Differences in goals and actors

involved in ACP practice between UK and Japan may reflect differences in cultural values (Fig 1). Patient autonomy(UK) vs patient dignity (Japan) and patient-centred (UK) vs family-centred (Japan) decision-making were some of the key differences with regards to ACP priorities and communication patterns.

Determining patient capacity was perceived fundamental by UK clinicians, whilst family's wishes took priority by JP clinicians. Both UK and Japan clinicians preferred to engage in withholding treatment discussions comparing to withdrawal. DNAR orders were routinely assessed in the UK, whilst performed only when 'disease worsening' in Japan. Balance between suffering and prolonging life was considered by both countries, albeit with different importance. Individual ICU culture, training in ACP and involvement of palliative care teams seem to influence variation in engagement and implementation of ACP practices in the different units.



Clinical recommendations

- The context specific values in EoL care, communication and decision-making practices, alongside integration of PC care and ACP education should be considered when initiating ACP interventions for the ICUs in different countries.
- Existing ICU frameworks on treatment limitation processes (treatment escalation planning, EoL decision-making, and treatment limitation decisions), could be utilized as the embedded framework to implement ACP.
- Alignment of reported patient and family wishes with actual trajectory of care and outcomes might be the most appropriate measure for quality of ACP interventions.

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5. 主な発表論文等

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| 2. 論文標題 Palliative care interventions in intensive care unit patients | 5. 発行年 2021年 |
| 3. 雑誌名 Intensive Care Medicine | 6. 最初と最後の頁 1415 ~ 1425 |
| 掲載論文のDOI（デジタルオブジェクト識別子） 10.1007/s00134-021-06544-6 | 査読の有無 無 |
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| 2 . 発表標題 oral presentation |
| 3 . 学会等名 International conference of Advanced Care Planning |
| 4 . 発表年 2023年 |

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〔 図書 〕 計0件

〔 産業財産権 〕

〔 その他 〕

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| 6 . 研究組織 | 氏名 (ローマ字氏名) (研究者番号) | 所属研究機関・部局・職 (機関番号) | 備考 |
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7 . 科研費を使用して開催した国際研究集会

〔 国際研究集会 〕 計0件

8 . 本研究に関連して実施した国際共同研究の実施状況

| 共同研究相手国 | 相手方研究機関 | | | |
|---------|----------------------------|--|--|--|
| 英国 | King's College London | | | |
| 英国 | London School of Economics | | | |
| 英国 | Martlets Hospice | | | |