

STUDY PROTOCOL

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Identification of unmet information needs among families of critically ill patients and their association with post-intensive care syndrome-family: protocol for a single-center cross-sectional study

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Abstract

Background Families of critically ill patients in the intensive care unit (ICU) need a variety of information about the patient. Meeting these information needs improves the quality of communication between the family and ICU staff, as well as reduces the risk of post-intensive care syndrome-family (PICS-F). However, information needs continue to be unmet, and information regarding which specific information needs are met or unmet is insufficient. Additionally, the unmet needs that affect PICS-F are unknown. Therefore, this study aims to identify the unmet information needs of families of patients admitted to the ICU in terms of communication with ICU staff and determine their association with PICS-F.

Methods This study will be a single-center cross-sectional study using a questionnaire survey. The participants will include family members of patients admitted to the emergency ICU of the Department of Emergency and Critical Care Medicine, Nippon Medical School Hospital in Japan. Eligibility for participation will be assessed from medical records, and family members of patients who meet the eligibility criteria will be identified and sent a questionnaire. PICS-F and unmet information needs will be assessed 1 to 12 months after patients leave the ICU. PICS-F assessment will include the evaluation of anxiety, depression, post-traumatic stress disorder, and prolonged grief disorder. Univariate and multiple logistic regression analyses will be used to examine the association between PICS-F and unmet information needs.

Discussion This study will fill a research gap in communication between ICU staff and families of ICU patients by examining the information that tends not to be provided or understood by families, thereby providing an understanding of the information that is likely to be an unmet information need. Additionally, this study can contribute to the development of future communication strategies by investigating which unmet information

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needs are associated with PICS-F risk, thus emphasizing the information needs that should be given priority when developing effective communication strategies.

Trial registration University Hospital Medical Information Network Center Clinical Trials Registry UMIN 000053813.

Keywords Communication, Information, Post-intensive care syndrome-family, Unmet need

Background

Families of patients admitted to intensive care units (ICUs) may experience anxiety, depression, and post-traumatic stress disorder (PTSD) after leaving the ICU [1–4]. Reportedly, families of patients who die in the ICU are more likely to experience, in addition to these symptoms, complicated grief symptoms associated with bereavement, which are termed prolonged grief disorder (PGD) [5–7]. The various psychiatric symptoms experienced by patients' family members after discharge from the ICU are referred to as post-intensive care syndrome-family (PICS-F), which is conceptualized as a syndrome consisting of anxiety, depression, PTSD, and PGD symptoms [8, 9]. The prevalence of anxiety symptoms of PICS-F is 15–24% and depressive symptoms is 17.9% at 1 to 6 months, PTSD symptoms is 33.1–49.0% at 3 to 6 months, and PGD symptoms is 5–46% at 3 to 12 months after ICU discharge [10]. These prevalence rates vary across studies and can be attributed to differences in study methods, such as the method and timing of the PICS-F assessment in each study, as well as to differences in the risk factors of the study participants.

Although various risk factors for PICS-F exist, “history of mental illness” and “female sex” are the most common. Other risk factors include “severely ill patient” and “spouse of the patient” [11]. Many of the risk factors for PICS-F are non-modifiable and are attributable to the sociodemographic characteristics of the patient and family. However, there are also risk factors attributable to the family's experience in the ICU, such as dissatisfaction with the medical care received by the patient and dissatisfaction with communication with the ICU staff [2, 3, 12–15]. A systematic review and meta-analysis reported that poor communication with ICU staff was a significant modifiable risk factor [11]. These risk factors differ from those attributable to sociodemographic characteristics in that they are modifiable, making them important factors for intervention by ICU staff. Several randomized controlled trials have reported that strategic interventions to improve communication between ICU staff and families reduce the risk of PICS-F [16, 17].

A critical factor that influences the quality of communication in the ICU is the explanation of the information needed by the family, such as what is happening and why certain things are being done for the patient, and meeting these information needs of the family improves the quality of communication [18]. The information needs

of families in the communication between ICU staff and family members vary [19–21], but the nature of the information needs that are particularly important to families have been identified and collated in a questionnaire, which is a list of the 21 most important questions asked by family members of patients in the ICU [22]. In the ICU, information is provided to the family within a limited timeframe; however, communication with the family can be a burden for ICU staff [23]. Furthermore, the information that ICU staff perceive as important to the family may differ from what the family perceives as important [22, 24], causing the information needs of the family to continually be unmet [25]. Therefore, various communication strategies have been developed to meet the information needs of families [26]. These strategies include the use of a question-prompt list based on identified family information needs [22, 27] and, more recently, the use of modern technology tools such as online applications [28–30].

The dissemination and implementation of these communication strategies in ICU practices are still in their infancy stage, and families may still have unmet information needs. However, little is known about trends in information needs that are currently being met and are unmet. Especially in Japanese ICUs, strategies to improve the quality of communication between the patient's family and ICU staff are rarely used, and the information provided to the family and the way it is communicated varies among ICU staff. Understand the met and unmet information needs of the family is necessary to implement future strategies. Additionally, the impact of communication strategies in the ICU on PICS-F risk reduction is limited [27–30]. The unmet information needs that are highly associated with PICS-F risk are unknown; therefore, further development of effective strategies is needed. To develop more effective strategies, it is necessary to identify unmet information needs that can increase PICS-F risk and to consider information needs that require focused intervention. This study aims to identify the unmet information needs of the families of patients admitted to the ICU regarding communication with ICU staff and determine their association with PICS-F.

Methods/Design

Study design and setting

This study will be designed as a single-center cross-sectional study using a questionnaire survey. Before submitting this protocol, we confirmed whether the design was suitable according to the STROBE checklist for cross-sectional studies (see Additional File 1). This study was approved by the Central Ethics Committee of the Nippon Medical School Foundation (approval no. M-2023-152; approval date: February 19, 2024). Additionally, the study was registered in the University Hospital Medical Information Network Center Clinical Trials Registry, Japan (registration was prior to participants enrollment [registration no.: UMIN 000053813]). The study population will include the family members of patients admitted to the emergency ICU of the Department of Emergency and Critical Care Medicine, Nippon Medical School Hospital in Japan between April 2023 and February 2024. Data will be collected from April to May, 2024.

Study participants

In total, 1,000 family members of patients admitted to the ICU who meet the eligibility criteria will be invited to participate in the study. The eligibility criteria will be determined by the inclusion criteria, which will be as follows: age of at least 18 years, blood relatives of family member or partner/key person of the patient admitted to the ICU, participation in a meeting with the physician regarding the medical care provided to the patient in the ICU, and family members of patients who will have an elapsed period of at least 1 month but not more than 12 months since they were discharged from the ICU. In addition, study participants who meet the inclusion criteria but have physical or cognitive impairments that make it difficult for them to respond to the questionnaire or are currently participating in another study will be excluded.

Study procedure

Eligibility for participation in the study will be assessed from medical records, and family members of patients who meet the eligibility criteria will be identified and sent an invitation letter, consent form, and questionnaire by mail inviting them to participate in the study. If they agree to participate in the study, they will be asked to return a signed consent form and a questionnaire with their answers, which will be used as the data for this study. In addition, data on the clinical characteristics of the patients will be extracted from their medical records and used in this study.

Measures

PICS-F is a syndrome consisting of anxiety, depression, PTSD, and PGD symptoms and is defined as a family psychiatric dysfunction after a patient is discharged from

the ICU [8, 9]. Each of the mentioned symptoms will be assessed in this study. PICS-F, unmet information needs, overall care satisfaction, and characteristics of the participants will be assessed using a questionnaire survey, and the clinical characteristics of the patient will be assessed using data extracted from medical records.

Anxiety symptoms

Anxiety symptoms will be assessed using the Generalized Anxiety Disorder-7 (GAD-7) questionnaire, a widely used screening tool for generalized anxiety disorder [31]. GAD-7 contains seven items on a 4-point scale. It has a total score of 0–21, wherein 5–9, 10–14, and 15–21 points indicate mild, moderate, and severe level of symptoms, respectively [31]. The cutoff score for symptom detection on GAD-7 is 10, and participants with a total score of 10 or higher will be considered to have anxiety symptoms [31]. The validity and utility of the Japanese version of GAD-7 have been confirmed [32, 33].

Depressive symptoms

Depressive symptoms will be assessed using the Patient Health Questionnaire-9 (PHQ-9) questionnaire, a widely used screening tool for major depressive disorder [34]. The PHQ-9 consists of nine items on a 4-point scale. It has a total score of 0–27, where 0–4, 5–9, 10–14, and 15–27 points indicate a normal, mild, moderate and severe level, respectively [34]. The cutoff score for symptom detection on the PHQ-9 is 10, and participants with a total score of 10 or higher will be considered to have depressive symptoms [34]. The reliability and validity of the Japanese version of the PHQ-9 have been confirmed [35, 36].

PTSD-related symptoms

PTSD-related symptoms will be assessed using the Impact of Event Scale-Revised (IES-R) questionnaire, a widely used screening tool for PTSD [37]. The IES-R questionnaire, with 22 items on a 5-point scale and a total score of 0–88, is factorized into three dimensions: intrusion, avoidance, and hyperarousal [37]. The cutoff score for symptom detection on the IES-R questionnaire is 25, and participants with a total score of 25 or higher will be considered to have PTSD-related symptoms [37]. The reliability and validity of the Japanese version of the IES-R questionnaire have been confirmed [38].

PGD symptoms

If the participant is a family member of a patient who died in the ICU, PGD symptoms will be assessed using the Brief Grief Questionnaire (BGQ), a screening tool for prolonged grief disorder [39]. The BGQ consists of five items on a 3-point scale and has a total score of 0–10 [39]. The cutoff score for symptom detection on the BGQ

is 8, and participants with a total score of 8 or higher will be considered to have PGD symptoms [39]. The reliability and validity of the Japanese version of the BGQ have been confirmed [40, 41].

Unmet information needs

The unmet information needs of families of patients admitted to the ICU will be assessed using the item list of the 21 most important questions asked by family members of patients in the ICU [22]. This list presents items of important information needs common to family members of ICU patients and consists of 21 items in 8 domains: “diagnosis,” “treatment,” “prognosis,” “comfort,” “interaction,” “communication,” “family,” and “post-ICU” [22]. For this study, the English version has been translated into Japanese with the developer’s permission. The Japanese version was prepared by examining the surface and content validities among researchers. Participants will be asked to select one of the following responses for each of the 21 items: “explanation was given, and I understood,” “explanation was given, but I did not understand,” “no explanation was given, but I wanted an explanation,” “no explanation was given, but I did not want an explanation,” or “I do not recall.” Items answered “explanation was given, but I did not understand” or “no explanation was given, but I wanted an explanation” will be evaluated as unmet information needs. The details of the question items are provided in Additional File 2.

Overall care satisfaction

Overall care satisfaction will be assessed using a single question. This question item was developed based on a nationwide questionnaire survey conducted among family members of patients with cancer in Japan [42] who were asked the question, “Overall, were you satisfied with the medical care the patient received at the ICU?” Participants will be asked to respond on a 6-point Likert scale (1 = absolutely dissatisfied, 6 = absolutely satisfied).

Characteristics of the participants

The following characteristics of the participants will be assessed: age, sex, last education, employment status, relationship with the patient, living with the patient, living with other family members, history of mental illness, current physical illness being treated, and current mental illness being treated.

Clinical characteristics of the patient

The following patient clinical characteristics will be assessed: age, sex, diagnosis, acute physiology and chronic health evaluation II scores, length of ICU stay, diagnosis of executive dysfunction at ICU discharge, positive delirium screening during ICU stay, duration of

invasive mechanical ventilation use during ICU stay, and use of invasive mechanical ventilation at ICU discharge.

Statistical analyses

Descriptive statistics will be calculated for each measurement. Categorical variables will be summarized using frequencies and proportions. Continuous variables will be presented using means and standard deviations if normally distributed or medians and interquartile range if not normally distributed. GAD-7, PHQ-9, IES-R, and BGQ scores will be converted to binary variables with cutoff scores to calculate the prevalence of anxiety, depression, PTSD, and PGD symptoms and the comorbidity of each symptom, respectively. Pearson’s correlation coefficients between GAD-7, PHQ-9, IES-R, and BGQ scores will also be calculated.

Furthermore, to evaluate the association between anxiety, depression, PTSD, and PGD symptoms and unmet information needs, univariate analyses such as Fisher’s exact test, Chi-square test, and Mann–Whitney U test will be conducted first to evaluate the association between each of the binary variables of GAD-7, PHQ-9, IES-R, and BGQ and unmet information needs, overall care satisfaction, characteristics of the participants, and clinical characteristics of the patient. In addition, multiple logistic regression analysis will be conducted using the variables that are found to be associated with $P < 0.200$ in the univariate analysis as independent variables and the binary variables of GAD-7, PHQ-9, IES-R, and BGQ as dependent variables, respectively, to evaluate their association from adjusted odds ratios and 95% confidence intervals. Similarly, multiple regression analysis with the continuous variables of the GAD-7, PHQ-9, IES-R, and BGQ scores as the dependent variables will be conducted as an exploratory analysis. Variables forced into the regression model will be confirmed to ensure that they are not multicollinearly based on the variance inflation factor (VIF); a $VIF \geq 5.0$ will be considered to represent multicollinearity [43]. All analyses were performed using SPSS version 26 software (SPSS Inc., Chicago, IL, USA).

Sample size considerations

The main analytical method used in this study will be multiple logistic regression analysis, with a sample size of 10 times the number of independent variables [44]. However, even when the sample size is 5 to 9 times the number of independent variables, the statistical problems (type I error $\geq 7\%$, relative bias $\geq 15\%$) are verified to be equivalent to those observed when the sample size is 10 times the number of independent variables [45]. Therefore, in this study, five times the number of independent variables will be set as the sample size required for analysis, and the maximum number of independent variables

entered into the logistic analysis will be 40 (21 items of unmet information needs, 1 item of overall care satisfaction, 9 items of characteristics of the participants, and 9 items of the clinical characteristics of the patient), and the sample size will be 200. This study will be conducted using a questionnaire for family members of patients admitted to ICUs in emergency departments in Japan—the study participation rate in similar studies has ranged from 12.5 to 32.0% [46, 47]. Considering these participation rates and assuming that the participation rate in this study will be approximately 20.0% with a sample size of 200, inviting approximately 1,000 family members to participate in this study will be appropriate.

Discussion

To the best of our knowledge, this is the first study to investigate met or unmet information needs of family members using the list of 21 most important questions asked by family members of patients in the ICU. The information needs of the families of ICU patients vary widely, and this list was developed after questioning a large sample of families and assessing how important each question was to them [22]. ICU staff should consider communicating with families to ensure that their information needs are met. However, in practice, these information needs are not met [25], which could be due to both inadequate information provided by the ICU staff and difficulties family members face in understanding the information provided. In cases such as unexpected ICU admissions, families also face difficulties obtaining information about the patient's condition [48], and ICU staff and the families have different perceptions of the appropriate information needed by the family members [22, 24, 49]. These limitations can result in unmet information needs. Furthermore, even when ICU staff attempts to fully explain certain information, such as the patient's prognosis, the family's understanding often differs from what the ICU staff intend to communicate [50]. Intensivist communication patterns have been found to affect a family's understanding of their loved one's prognosis in the ICU [51]. Because of these discrepancies in understanding, the information needs of the family may not be met, although the ICU staff may perceive that they have provided sufficient information. Therefore, our study will investigate whether family members were provided with the information they wanted for each of the 21 information needs provided in a questionnaire and whether they understood the information provided. This study will fill a research gap in communication between ICU staff and families of ICU patients by examining the information that tends not to be provided or understood by families and providing an understanding of the information that is likely to be an unmet information need.

Additionally, this study will explore the relationship between identified unmet information needs and PICS-F. Poor-quality communication between ICU staff and a patient's family is a risk factor for PICS-F [11], and improving the quality of communication is undoubtedly important to prevent the occurrence of unmet information needs. The impact of communication strategies to meet family information needs on PICS-F has been studied in several clinical trials [27, 29], but no consensus has been reached. Additionally, these trials have not evaluated the information needs of the family that are met by the intervention and to the extent to which they are met. The mechanisms by which these needs are met affect the risk of PICS-F more than the risk of other factors [27, 29]. Therefore, we will examine which information needs of families, met or unmet, are associated with the risk of PICS-F and provide a mechanistic understanding of the impact of communication strategies to meet family information needs on PICS-F occurrence. This study will contribute to the development of suggestions on the information needs to focus on when developing more effective communication strategies.

Abbreviations

GAD-7	Generalized Anxiety Disorder-7
IES-R	Impact of Event Scale-Revised
ICU	Intensive care unit
PHQ-9	Patient Health Questionnaire-9
PICS-F	Post-intensive care syndrome-family
PTSD	Post-traumatic stress disorder
PGD	Prolonged grief disorder

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12904-024-01599-w>.

Supplementary Material 1: STROBE Statement—Checklist of items that should be included in reports of cross-sectional studies.

Supplementary Material 2: Questionnaire of the 21 most important questions asked by family members of patients in the intensive care unit.

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Author contributions

YI, TH, MS, MA, YO, YS, and SY conceptualized and designed the study. YuS, EY, AT provide expertise in study conduction. YI wrote the manuscript. All authors read and approved the final manuscript.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

This study was approved by the Central Ethics Committee of the Nippon Medical School Foundation (approval no. M-2023-152; approval date: February 19, 2024).

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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