

## REVIEW ARTICLE

# Health Literacy of ICU Patients' Family: A Review

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### ABSTRACT

Family health literacy supports critically ill patients during intensive care unit (ICU) stay. This review aimed to provide an overview of family health literacy. Literature was searched in Medline, Scopus, SINTA, PubMed, Google Scholar, Web of Science, Science Direct and Pro-Quest databases. This review followed PRISMA protocol. Each study was assessed for its quality and risk of bias by two reviewers independently using JBI instruments. Any disagreements were resolved by consensus. Seven studies were included in the review, in which the patient's family requires information regarding the patient's diagnosis, treatment, state of comfort, interaction, and prognosis. Some IT-based interventions were proven to be effective in enhancing family health literacy. Meta-analysis was unable to be performed due to variations of the design of included studies and outcomes measured. It is concluded that further study is required to investigate the health literacy of the family of ICU patients.

**Keywords:** Health literacy, Intensive care unit, Family, Health outcomes, Information seeking

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### INTRODUCTION

Most Intensive Care Unit (ICU) patients are in a life-threatening condition and have several needs, including family and friends' involvement and support (1). The family intends to be involved in patient's care during ICU stay (2-4) and can provide a supporting role to help patients meet their needs. These include emotional and psychological support, partners of health personnel or other family members and patients, and fulfilling patients' spiritual and instrumental needs (5,6). However, some patients' family or caregivers might not know what they have to do for their family members who are being treated in the ICU (7). The patient's family lack of understanding and skills might create a care burden (7), which, in turn, creates difficulties for ICU nurses where they have to explain to the family about the patient's condition, the role of the family during visiting hours, the type of care needed and the things that could be harmful. One of the main strategies to avoid these problems is improving a patient's family health literacy. Health literacy is a person's ability to both seek and use information related to health, healthcare, and health systems to maintain and improve health (8). Low health literacy among family or caregivers may enhance risks

associated with patient safety.

Studies conducted in various settings revealed the importance of health literacy, such as health determinant, health mediator and moderator (9), predictors of fluid management of patients undergoing hemodialysis (10), pre-eclampsia knowledge (11), asthma control (12), emergency department visit decision (13), mammography decision (14), help-seeking behavior (15), and self-care (16). Some reviews have explained the health literacy of individual or family in several populations, i.e. health literacy of the general population regarding the Covid 19 pandemic (17), HIV patients (18-20), cancer (21) and many more. However, little is known about family health literacy during patient ICU stay and its effect on patients. This review aimed to explore ICU patients' family health literacy, especially about the information needed by family members and what intervention might be beneficial.

### MATERIALS AND METHODS

#### Search strategy

Articles were searched in electronic databases: Medline, Scopus, SINTA, PubMed, Google Scholar, Web of Science, Science Direct and Pro-Quest. The search used a combination of keywords and medical subject headings (MeSH) of health literacy, information seeking, attitude to health, literacy, health, ICU, critical care, family, relative\*, caregiver, loved ones, and infection.

Articles were also identified from references of crucial studies. There was no limitation of language or year of publication applied during the electronic search process. The search yielded 4,595,065 records in total.

**Study selection and quality assessment**

Study selection was guided by PRISMA protocol. Firstly, an electronic search of nine databases was performed and yielded 4,595,065 records. These were then exported to a referencing manager and checked for duplication; 4,594,750 duplications were removed. The remaining 315 records were removed for duplication, and the title and abstract were screened. Finally, two authors evaluated abstracts and decided on articles included in the review. In the following step, the authors reviewed full papers based on inclusion and exclusion criteria (Table I). The article was excluded from the review when both authors agreed that the article did not meet the inclusion criteria. Studies which did not meet eligibility criteria were excluded, and the final papers were critically appraised.

**Table I: Inclusion and exclusion criteria**

Criterion	Inclusion	Exclusion
Period time	All period time	none
Language	English, Bahasa Indonesia	-
Type of article	Original research	Review paper, unpublished research, protocols, editorials
Study type	Survey, qualitative study, experiment study	Case report, case series, case-control
Population	Family of patients in ICU	none
Setting	Any ICU	none
Study focus	Health literacy and outcomes	Literacy and its relationship with health

Seven studies were finally included in the review, critically appraised for quality and risk of bias by two authors independently using JBI (Joanna Briggs Institute) critical appraisal instruments. Each study was graded according to the appropriateness and adequacy of explanation in regard to the appropriateness of sample, description of inclusion and exclusion of the sample, description of subjects and setting, appropriateness of measurement of outcomes and instrument used, identification of confounding and adequacy of controlling it, and appropriateness of data analysis (22). The study employed a qualitative approach and was assessed based on congruity between its philosophical perspective and research methods, between research methods and research question, data analysis, and results from interpretation, the researcher him/herself, participants of the study, ethics, and how a conclusion was drawn from the data and their interpretation (23).

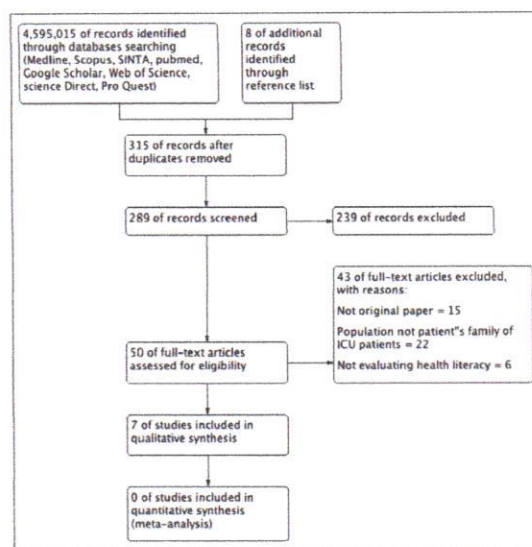
Each quality rating was rated into numeric values (yes = 1, no = 0, unclear = 0, not applicable = 0) which further contributed to the composite percentage for the

study. Each author evaluated and scored each study independently, and any disagreements during the evaluation process were resolved by discussion and consensus among authors. The score of each examiner was totaled and averaged to obtain the final score of the study. Each study was then rated as good if a total score was greater than or equal to 50% or rated as poor if the total score was less than 50%.

Ethics approval was obtained from Faculty of Nursing Universitas Airlangga Ethics Committee before commencement of the study.

**RESULTS**

The whole search process can be seen in Figure 1. Seven papers passed through the selection process and were included in the review. The number of included papers indicates that studies regarding health literacy or interventions to improve the health literacy of ICU patients or relatives were relatively sparse.



**Figure 1: Family Health Literacy PRISMA study flow diagram**

As shown in Table II, of seven studies, two were intervention study, two surveys, and three qualitative studies. All studies involved ICU patients' family and some of them also involved healthcare professionals. All studies included in the review had good quality.

**Information needed by family members**

Three studies explored the topic needed to know by family members to enhance their health literacy. The topics were knowledge of condition (diagnosis, treatment, patient's comfort, interaction) and prognosis, how to communicate with patients and healthcare professionals, how family might help, family decision-making, spiritual need, caregiver stress, post-ICU and end of life issue (24–26).

**Table II: Summary of Study Characteristics of ICU patient's family health literacy**

Authors, Year	Objective	Study Population, sample size	Study design	Outcome measured	Quality
(Young, Stephens, & Goldsmith, 2017)	To explore family caregivers' experience	Family caregivers, ICU, 18	Qualitative	Key findings: communication: agency, coordinated communication, and caregiver's evolving role	Good
(Peigne et al., 2011)	To develop of list of questions asked by family members of ICU patients	Families, 14 Panel of nurses and MD, 28 Surveys of nurses and MD in 14 ICUs	Qualitative study	21 of 2,135 questions were rates as important questions asked by family members	Good
(Hoffmann et al., 2018)	To understand what topics are most important for ICU patients' relatives	Relatives, nurses, doctors and other health professionals, 336	Survey at four different Facebook group	Important topics are crisis, family participation, etc.	Good
(Suarez et al., 2020)	To understand the perception of health care team regarding medical interpreters' role	MD, 16 Nurses, 12 Interpreter, 12	Qualitative, semi structured interview	Role of the interpreters: interpret health professionals' language, health literacy guardian, cultural brokers	Good
(Mistraletti et al., 2019)	To develop a specially designed website to improve health literacy	ICU relatives of critically ill patients, 2100	RCT, multicenter	Health literacy, burden of traumatic experience, anxiety and depression	Good
(Mistraletti et al., 2017)	To measure effect of a family information brochure and social networking sites on ICU experience of patients' relatives	Caregivers of mixed ICU, 332	Prospective before and after	Health literacy (prognosis, procedures), anxiety, depression, stress	Good
(Lakshmanan, Santo, McCormick, & Belfort, 2014)	To describe prevalence of internet and email access among parents, their preference for completing questionnaire and predictors of access and preference	Parents of neonatal ICU, 270	Cross-sectional survey	Health literacy	Good

### The need for health interpreter to enhance family health literacy

Suarez et al. (2020) highlighted the need for a medical interpreter to deliver information to family members. The study concluded that a health interpreter facilitated patient's family health literacy by interpreting health professionals' language which was difficult for family members to understand, and providing a health literacy guardian, and cultural brokers (27).

### Interventions available to enhance health literacy of ICU patients' family members

Three intervention researches studied the effect of IT-based media to deliver information to a patient's family during a patient's ICU stay. Although the studies employed a variety of designs (RCT, quasi-experiment, and survey) and different methods, web-based brochure (28,29), and email and internet access (30), the three studies agreed that the use of information technology helps enhance family members' health literacy.

## DISCUSSION

Published literature in this study included in the review were Peigne et al. (2011), Young et al. (2017) and Hoffmann et al. (2018), who highlighted the importance of information for family members to enhance their health literacy (24–26). The most crucial information that the family needs from the healthcare professional is the patient's condition in the ICU. Another important thing they want to know is how they might help their loved one. Information delivery sometimes is difficult for both healthcare professionals and family members because of the use of medical jargon and different

levels of knowledge regarding healthcare; thus, a health interpreter might be helpful in some way.

Currently, some interventions have been designed and tested, aiming at improving family health literacy; these are mainly IT-based for ease of use and easy for the family to understand and can be retrieved several times by family members without asking healthcare professionals. However, limited studies and methods used make it impossible to perform a meta-analysis to investigate the impact of these interventions.

This review should be interpreted in the context due to the number of studies included and the population represented. The studies were conducted in developed countries with a reasonably good level of literacy of its population in general. In general, the impact of the intervention was not able to be calculated due to variations of study design, intervention applied, and outcome measurement. Future study can be built on this review to elaborate the health literacy of the family of ICU patients.

## CONCLUSION

This review highlights topics important for a family member and method of delivering information that helps enhance family member's health literacy. Delivering accurate and complete information about a patient's condition to the patient's family is a responsibility that nurses and physicians must undertake. Submission of information in plain language that is easy to comprehend must be a priority in order to avoid misperceptions. This is an example of how capacity development through the use of IT-based interventions may be used to increase

reading skills among the patient's family members in this situation. The findings of this study can, therefore, give an overview of information on the patient's family's literacy needs, which can be useful for both health workers and hospitals in finding a good balance.

#### ACKNOWLEDGEMENTS

This research was funded by Faculty of Nursing, Universitas Airlangga Indonesia.

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