

## Family Intensive Care Unit Syndrome: An Integrative Review

### Abstract

**Background:** Hospitalization in the Intensive Care Unit (ICU) brings about psychological and physical symptoms in patients' family members. Family Intensive Care Unit Syndrome (FICUS) is a term used to explain the psychological symptoms of the family of a patient in response to the patient's admission to the ICU. The purpose of this study was to define FICUS along with its symptoms and predictors. **Materials and Methods:** The Web of Science, PubMed, Scopus, Google Scholar, and SID databases were searched for literature published in 2005–2018 with the keywords "FICUS," "intensive care unit," "family," "caregivers," "anxiety," "depression," and "post-traumatic stress disorder" in their title and abstract. The strategy for conducting an integrative review provided by Whittemore and Knafl (2005) was used in this study. **Results:** Twenty articles were included in the final data analysis. Following the patient's admission to the ICU, family members experience multiple psychological symptoms such as FICUS. The most commonly reported symptoms were anxiety, depression, post-traumatic stress disorder (PTSD), complicated grief, sleep disorder, stress, and fatigue. The low education level, having a critically-ill spouse, adequate support, financial stability, preference for decision-making, understanding of the disease process, anxiety, depression, or previous acute stress were predictors of FICUS. **Conclusions:** On the basis of the results, families also experience physical symptoms, so the FICUS is not limited to the occurrence of psychological symptoms. This study found that there is no universal definition for the term "FICUS" in the research literature. Thus, further research is needed to explore FICUS in the health field.

**Keywords:** Anxiety, depression, family, intensive care units

### Introduction

The importance of treating patients in the family has led to a change in the attitude toward treatment from client-centered to family-centered care.<sup>[1]</sup> Family-centered care is defined as a participatory decision-making approach, which allows for the participation of the patient's family. Increased awareness of the role of the family in the Intensive Care Unit (ICU) has prompted the participation of families in the provision of intensive care.<sup>[2,3]</sup> Studies show that families often suffer from depression, anxiety, dissatisfaction, and Post-Traumatic Stress Disorder (PTSD) after the hospitalization of their patient in the ICU.<sup>[3-5]</sup> Moreover, the family is often in the surrogate decision-maker position for the support and care of the patient.<sup>[6]</sup> Evidence suggests that supporting family participation in caring for loved ones may lead to improved patient outcomes.<sup>[7]</sup>

The results of studies show that hospitalization in the ICU is stressful for families.<sup>[8-10]</sup> As patients are unexpectedly hospitalized in the ICU, family members do not have enough time to deal with it. Therefore, they tend to experience it as a life-threatening crisis. This crisis can disrupt their normal life and functions.<sup>[3,5,11]</sup> Previous studies have reported a high prevalence of anxiety (70%–80%), depression (35%–70%), PTSD (54%), and physical and psychological symptoms such as fatigue, grief, and fear (80%) in the family members of ICU patients.<sup>[12-15]</sup>

Following the emergence of numerous psychological symptoms in the family members of ICU patients, the Society of Critical Care Medicine (SCCM) (2010) coined the new term Post Intensive Care Syndrome-Family (PICS-F) to address such families.<sup>[3]</sup> This syndrome indicates a disorder in the family members following the patient's discharge from the ICU.<sup>[3,16]</sup>

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During ICU hospitalization, psychological symptoms arise in many family members, a phenomenon which is referred to as Family Intensive Care Unit Syndrome (FICUS). FICUS is defined as morbidity and impairment experienced by the family members of patient admitted to ICU wards.<sup>[17-19]</sup>

The incidence of FICUS can have different consequences, including impairment in the decision-making process among family members.<sup>[17]</sup> As in most cases, ICU patients are incapable of participating in their own treatment processes and making decisions in this regard due to their condition, physicians and nurses rely on their families to choose and implement treatment and care for them.<sup>[20]</sup> Attention to the families of ICU patients and managing possible disorders in them will increase their participation and decision-making capacity in improving the treatment and care of their patients, in addition to their own health.

Due to the lack of specialized tools, dispersion of data, and unclear symptoms of FICUS, at the moment, there is no clear definition for FICUS. Moreover, the existing definitions are based on definitions of similar concepts. In recent years, researchers' interest in surveying the mental and physical disorders of family caregivers of the critically-ill has increased. The approach of most researches toward symptoms of FICUS has been quantitative. However, the concept of individual experience cannot be well investigated through quantitative studies. The integrative review is a combination of empirical and non-empirical data that encompasses broad goals such as defining concepts and reviewing theories and evidence.<sup>[21]</sup>

FICUS has always been of interest in professional literature, research, and politics; thus, it seems appropriate to conduct an integrative review on this phenomenon. Therefore, this integrative review was conducted with an analytical approach and the combination of quantitative and qualitative methodology to define FICUS along with its symptoms and predictors.

## Materials and Methods

This integrative review was designed based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist. The aim of this study was to define FICUS, and its symptoms and predictors. This literature review was conducted in 2019. Integrated review is the most comprehensive methodological approach to reviewing and understanding phenomena in empirical and non-empirical studies. Whittemore and Knaff<sup>[21]</sup> have provided an outline of the stages of an integrative review to aggregate the data of studies with diverse methods. They used this framework to perform an integrated review in nursing education based on the four components of problem identification, literature search, data evaluation, and data analysis presentation.<sup>[21]</sup>

1. *Problem identification phase:* The family members of the patient in the ICU could potentially suffer from physical

and psychological symptoms. The combination of their psychological symptoms is known as FICUS, PICS-F, and burden.<sup>[17]</sup> Due to the presence of different definitions for this syndrome and the presence of "boundary concept," it is necessary to clarify this concept and its attributes

2. *Literature search phase:* The electronic databases of PubMed, Scopus, Web of Science, SID, and Google Scholar were searched for peer-reviewed articles published between January 2005 and April 2018. The searched keywords were "FICUS," "intensive care unit," "family," "caregivers," "anxiety," "depression," and "post-traumatic stress disorder." These keywords were combined using Boolean operators "AND" and "OR." An example of a Scopus database search strategy is as follows: (TITLE-ABS-KEY) "Intensive Care Unit" AND TITLE-ABS-KEY ("Family" OR "Caregiver") AND TITLE-ABS-KEY ("Anxiety"). The inclusion criteria were a) English and Persian language, b) articles published between 2005 and 2018, and c) presence of the keywords in the title and abstract. Papers were excluded if they were conference abstracts. In addition, review articles were not included
3. *Data evaluation phase:* The titles and abstracts of 1887 articles were reviewed in terms of relevance. The overview of these studies revealed a diverse range of empirical studies, conference abstracts, dissertations, letters to the editor, and articles in other languages. The authors of this article reviewed the abstract of each article at least once. After a critical reading of the abstracts, 32 papers were included in critical analysis. Finally, a deeper examination of these articles revealed 20 of them to be suitable for analysis. The 4-member research team evaluated the data and the qualitative scoring of the searched literature using the initial coding sheet. The maximum score was 5 and a score of 3 and above was considered as the inclusion criterion for the article. To assess the quality and the risk of bias, 3 reviewers independently evaluated the final studies included in the research based on the Strengthening the Reporting of the Observational Studies in Epidemiology (STROBE) statement and Consolidated Criteria for Reporting Qualitative Studies (COREQ). The STROBE checklist contains 22 items that are essential for an observational (cohort, case-control, and cross-sectional) study. The articles that received 15.5 points were included in the analysis.<sup>[22]</sup> The authors of this paper used the COREQ as a checklist to report on the important aspects of methodology, context, findings, analyses, and interpretations<sup>[23]</sup>
4. *Data analysis phase:* This phase of the integrated review included the following recommended steps: (a) data reduction, (b) data display, (c) data comparison, and (e) conclusion drawing and verification. This is a systematic approach that eliminates the risk of bias, that is, unwanted deletion or inclusion of studies in the analysis process.<sup>[21]</sup>

Then, all articles were transferred to the reference management system in a regular manner. Duplicate copies were removed and 198 articles were screened using the titles and abstracts. During the screening process, 157 articles were excluded based on the inclusion criteria and 12 articles were excluded due to lack of experimental research criteria. In order to ensure the extraction of all the relevant articles, the screening and selection process of the articles was carried out according to the PRISMA guideline [Figure 1]. In next step, by data display and comparison, the key study components including the author's name, the year of publication, sample and setting, research design, instrument, and major findings were compared across the 20 studies [Table 1].

### Ethical considerations

The research (ethics code: IR.BMSU.REC.1396.561) was approved by the Ethics Committee of Baqiyatallah University of Medical Sciences, Iran.

### Results

Finally, 20 studies were included in this review. The majority of studies were quantitative studies; and qualitative studies were few. The main elements of these studies are presented in Table 1. The review of the articles

posited many psychological and physical symptoms in the family of ICU patients, including anxiety, depression, PTSD, complicated grief, sleep disorder, stress, and fatigue. In addition, the predictors of FICUS have been partly determined in studies. In line with the approach taken in previous studies, FICUS and PICS-F have also been discussed as a combination of psychological symptoms.

### Family intensive care unit syndrome

Decision-making impairment in the families of patients admitted to the ICU, and long-term or acute hospital care is called FICUS.<sup>[17,24]</sup> The experience of multiple physical and psychological disturbances by family members after the discharge of the patient along with FICUS has been reported as a burden and PICS-F.<sup>[3,25]</sup> The most significant finding of the review was that there is no universal definition for FICUS. According to the results of studies, FICUS is the combination of psychological, physical, and social relationship impairment symptoms in the family members of patients when admitted to an ICU.

### The symptoms of family intensive care unit syndrome

Studies on family caregivers of critically-ill patients are mainly focused on mental and physical disorders during the hospitalization of the patient in the ICU or acute long-term care settings. The families of ICU patients experience multiple symptoms including anxiety,<sup>[16,17,26-30]</sup> depression,<sup>[9,17,26,28,29,31]</sup> stress,<sup>[10,17,29,32,33]</sup> PTSD,<sup>[13,16,17,26,34-36]</sup> grief,<sup>[16,26,36,37]</sup> sleep disorders,<sup>[11,27,38-40]</sup> social problem-solving abilities,<sup>[41]</sup> sense of helplessness,<sup>[42]</sup> fatigue and functional impairment.<sup>[11,13,43]</sup> Regarding the frequency of symptoms in the studies, anxiety was one of the most common disorders experienced by the families of ICU patients. The studies have reported family anxiety levels to be 80%,<sup>[44]</sup> 73.40%,<sup>[45]</sup> and 70%,<sup>[16]</sup> higher in women than in men. The rate of depression in the family members has been calculated to be 70%,<sup>[46]</sup> 35.40%,<sup>[45]</sup> and 35%<sup>[16]</sup> higher in women than in men. According to the results of the studies, nearly half of the families experienced a high level of PTSD on admission of the patient and during hospitalization in the ICU.<sup>[12,31]</sup> Sleep disorders and fatigue<sup>[47]</sup> have been reported in most families. The frequency of sleep disorders was reported as 64.30% on admission and 53.60% after discharge.<sup>[38]</sup> Other symptoms experienced by family members included grief,<sup>[16,26,36,37,48]</sup> social process impairment,<sup>[41]</sup> and sense of helplessness.<sup>[42]</sup>

### The predictors of family intensive care unit syndrome

The demographic risk factors of FICUS include the age of the patient, female gender, low education level, and having a critically-ill spouse. Other factors include distance from the hospital, adequate support, financial stability, preference for decision-making, understanding of the disease process, religiosity, satisfaction with care, Quality Of Life (QOL), sleep status, anxiety, and depression or previous acute stress.<sup>[3,16,24,48,49]</sup>

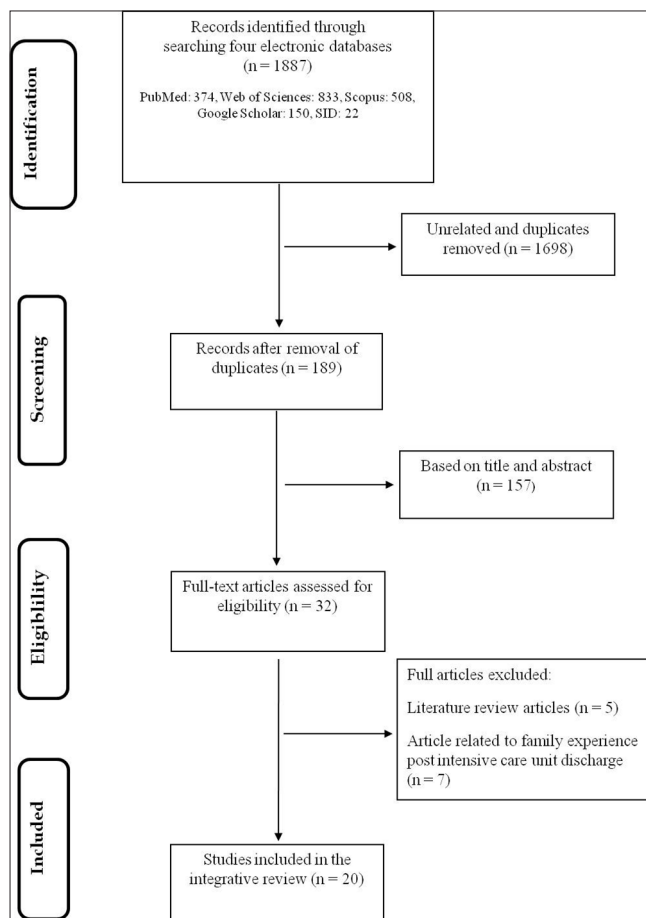


Figure 1: The process of selecting articles based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)

**Table 1: Studies included in the integrative review**

Authors	Title	Sample and setting	Research design	Instruments	Major finding
Askari <i>et al.</i> <sup>[9]</sup>	Psychological reactions of family members of patients in critical care units in Zahedan	244 family members	Descriptive, analytical study	Depression Anxiety Stress Scales (DASS)	Overall, 68%, 57.30%, and 46.70% of the patients' family members had moderate-to-very severe anxiety, depression, and stress, respectively
Azoulay <i>et al.</i> <sup>[31]</sup>	Risk of Post-traumatic Stress Symptoms in Family Members of Intensive Care Unit Patients	284 family members	Longitudinal study	Impact of Event Scale (IES)	Post-traumatic stress disorder was found in 94 (33.10%) family members.
Anderson <i>et al.</i> <sup>[26]</sup>	Posttraumatic Stress and Complicated Grief in Family Members of Patients in the Intensive Care Unit	50 family members	Prospective, longitudinal cohort study	Hospital Anxiety and Depression Scale (HADS), Impact of Event Scale (IES), and Inventory of Complicated Grief (ICG)	Anxiety, depression, posttraumatic stress, and complicated grief were observed in 42%, 16%, 35%, and 46% subjects, respectively
Alfheim <i>et al.</i> <sup>[12]</sup>	Post-traumatic stress symptoms in family caregivers of intensive care unit patients: A longitudinal study	211 family caregivers	Longitudinal study	Impact of Event Scale-Revised (IES-R) and Herth Hope Index	Post-traumatic stress disorder was observed in 54% of the participants.
Chang <i>et al.</i> <sup>[39]</sup>	Stress, stress-related symptoms and social support among Taiwanese primary family caregivers in intensive care units	87 family caregivers	Cross-sectional, descriptive, correlational study	Impact of Event Scale-revised (IES-R), General Sleep Disturbance Scale, Lee's Fatigue Scale, Norbeck Social Support Questionnaire (NSSQ) and one open-ended question	Poor sleep quality and fatigue were reported by the participants.
Choi <i>et al.</i> <sup>[43]</sup>	Health risk behaviors in family caregivers during patients' stay in intensive care units: A pilot analysis	50 family caregivers	A prospective, longitudinal, descriptive design	Caregiver Health Behavior instrument, Epidemiologic Studies Depression Scale, Brief Zarit Burden Interview	One or more health risk behaviors, depression, and burden were observed in 94%, 90%, and 36% of family members, respectively
Choi <i>et al.</i> <sup>[47]</sup>	Psychological and Physical Health in Family Caregivers of Intensive Care Unit Survivors: Current Knowledge and Future Research Strategies	28 family caregivers	Descriptive, repeated measures design	Pittsburgh Sleep Quality Index (PSQI) and objective sleep/wake variables (SenseWear Armband)	Poor sleep quality was observed in 64.30% of the participants during ICU admission and in 53.60% of participants post-ICU discharge.
Davidson <i>et al.</i> <sup>[3]</sup>	Family response to critical illness: Post-intensive care syndrome family	-	Concise definitive review	-	Anxiety, acute stress disorder, posttraumatic stress, depression, and complicated grief were observed in the participants.
Fumis <i>et al.</i> <sup>[15]</sup>	Emotional disorders in pairs of patients and their family members during and after ICU stay	471 family members and 289 patients	Prospective study	Hospital Anxiety and Depression Scale (HADS), Impact of Event Scale (IES)	Anxiety, depression and post-traumatic stress disorder symptoms were observed in family members.
Kentish-Barnes <i>et al.</i> <sup>[37]</sup>	Complicated grief after death of a relative in the intensive care unit	Relatives of 475 adult patients	Prospective, observational study	Hospital Anxiety and Depression Scale (HADS), Revised Impact of Event Scale (IES-R) for PTSD symptoms questionnaires	Complicated grief symptoms were observed in 52% of the participants.

*Contd...*

Table 1: Contd...

Authors	Title	Sample and setting	Research design	Instruments	Major finding
Maghsoudi <i>et al.</i> <sup>[33]</sup>	Family experiences of patients admitted in Intensive Care Unit (ICU)	14 family members	Phenomenology	In-depth interviewing and diary method for gathering data	Severe stress in physical, emotional, psychological, and social concepts were observed in the participants.
McAdam <i>et al.</i> <sup>[13]</sup>	Symptom experiences of family members of intensive care unit patients at high risk for dying	74 family members	Prospective, cross-sectional study	Impact of Event Scale-Revised (IES-R), Hospital Anxiety and Depression Scale (HADS), Edmonton Symptom Assessment Scale-Revised, Family Crisis-Oriented Personal Scales, and Family Adaptability and Cohesion Evaluation Scale	Traumatic stress, anxiety, depression, fatigue, sadness, and fear were observed in 57%, 80%, 70%, and more than 80% of the subjects, respectively.
Pochard <i>et al.</i> <sup>[45]</sup>	Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multicenter study	544 family members	Prospective multicenter study	Hospital Anxiety and Depression Scale (HADS)	The prevalence of symptoms of anxiety and depression were 73.40% and 35.30%, respectively
Sullivan <i>et al.</i> <sup>[42]</sup>	Learned helplessness among families and surrogate decision-makers of patients admitted to medical, surgical, and trauma ICUs	460 family members	Observational survey study	Learned Helplessness Scale, Perceived Stress Scale	A high level of learned helplessness and stress was reported in the subjects.
Navidian <i>et al.</i> <sup>[29]</sup>	Psychological Reactions of Family Members of Patients Hospitalized in Critical Care and General Units Compared with General Population	135 family members	Descriptive, cross-sectional study	Depression Anxiety Stress Scales (DASS-21)	Stress, anxiety, and depression were observed in the subjects.
McKiernan and McCarthy <sup>[49]</sup>	Family members' lived experience in the intensive care unit: A phenomenological study	6 family members	Phenomenological method	In-depth interviews	The four main categories of need to know, making sense of it all, being there with them, and caring and support were identified.
Plakas <i>et al.</i> <sup>[48]</sup>	The experiences of families of critically ill patients in Greece: A social constructionist grounded theory study	25 relatives of critically ill patients	A social constructionist grounded theory study	In-depth interviews	The seven categories of intense emotions, vigilant attendance, religiosity, the changed identity, information, caring, and dignity were identified.
Hwang <i>et al.</i> <sup>[30]</sup>	Anxiety and depression symptoms among families of adult intensive care unit survivors immediately following brief length of stay	106 family members	Prospective, single-center observational cohort study	Hospital Anxiety and Depression Scale (HADS)	Anxiety and depression were, respectively, observed in 8.30%-20.70% and 4.20%-8.60% of the participants.
Day <i>et al.</i> <sup>[53]</sup>	Sleep, anxiety, and fatigue in family members of patients admitted to the intensive care unit: a questionnaire study	94 family members	Questionnaire study	General Sleep Disturbance Scale (GSDS), Beck Anxiety Index (BAI), and Lee Fatigue Scale (LFS)	Moderate-to-severe sleep disturbance and fatigue, and mild anxiety were reported in by the subjects.
Verceles <i>et al.</i> <sup>[50]</sup>	Half of the family members of critically ill patients experience excessive daytime sleepiness	28 family caregivers	Longitudinal study	Pittsburgh Sleep Quality Index (PSQI)	Poor sleep quality was observed in the participants in the long run.

These symptoms begin at the time of admission and persist until several months later. Stress is one of the most important predictors of these symptoms in the patients' families. Moreover, poor sleep quality and irregular sleep-wake rhythm are among the main contributing factors in the occurrence of PICS-F.<sup>[39]</sup> In addition, sleep deprivation and inadequate rest have been considered as the risk factors threatening the health of ICU patients' families and causing dysfunction in them.<sup>[43,50]</sup>

## Discussion

On the basis of the philosophy of family-centered care, we expect the family to participate in decision-making and patient care. However, family members of patients experience numerous problems that they are sometimes incapable of managing. In this integrated review, FICUS was defined, and its symptoms and predictors were explored.

To the researchers' best knowledge, this was the first integrated review that was not limited to a particular research field. The lack of a universally accepted definition for FICUS in research literature is problematic for several reasons. First, the dimensions of the concept are not clear enough. The current definitions mostly rely on psychological symptoms, and the available literature places emphasis on the occurrence of physical symptoms in the families of patients in the ICU. Second, the emphasis of the studies is on the symptoms experienced by families after the patient is discharged from the ICU. Accordingly, the definitions accompanying the concept have been provided in the PICS-F framework. Third, the conceptual framework of the concept deals with the role of the family and their involvement in the issue of healthcare. Thus, the experiences of family members will differ in terms of the dimensions of the concept.<sup>[51]</sup>

Recognizing the symptoms of FICUS was one of the objectives of this study. The findings of this review show that when a patient is admitted to the ICU, his/her family members tend to experience a great deal of stress in physical, psychological, and social dimensions. The most common psychological symptoms experienced by the families of ICU patients are anxiety, depression, stress, and PTSD at different severities.<sup>[52]</sup> In addition, they may ignore their basic needs such as food, sleep, and bathing. This can lead to a reduction in their ability to cope with the existing problems and strains.<sup>[33]</sup> These disorders can persist for days after the discharge of the patient, and their intensity can decrease or increase in accordance with the conditions. Fatigue and sleep deprivation<sup>[27,38,50,52]</sup> are other symptoms reported in the family members of ICU patients, which have consequences such as cognitive dysfunction and impaired decision-making in the treatment process.<sup>[53]</sup>

On the basis of the evidence, the occurrence of psychological symptoms is often associated with the signs of fatigue, sleep disorders, anxiety, and depression

at different severities. One of the greatest impacts of sleep disorders is on daily living activities and the cognitive function of family members. In addition to the above-mentioned facts, sleep disorder is also associated with fatigue.<sup>[54]</sup> The high frequency of anxiety, depression, and PTSD in ICU patients' families can be observed even after the discharge of the patient.<sup>[5]</sup>

The symptoms of the families of the patients admitted to the ICU have been examined using various and sometimes nonspecialized tools, and accordingly, there are contradictions in the reports. Due to the tools used, most of the psychological symptoms have been reviewed and reported, and the physical symptoms have been underestimated. Although there are currently tools for risk assessment, specialized and principal examination requires specialized and practical tools. Hence, recognizing FICUS symptoms can be helpful in designing specialized tools to better understand the concept. Furthermore, with regard to the reported symptoms within a specified time frame, a well-established planning procedure may be adopted for prevention and management, considering the incidence of FICUS.

Another objective of this review was to identify the predictors of FICUS. Understanding these factors will definitely create a better approach to assessing and managing disorders. In addition, accurate planning can be proportionally made for purposeful interventions within the appropriate period to protect the health of family members. Maghsoudi *et al.*<sup>[33]</sup> and Plakas *et al.*<sup>[48]</sup> reported the spirituality, religiosity, and intellectual experience of families as effective factors in enhancing feelings of hope, enduring a difficult situation, and maintaining health. Other influential factors in this regard include gender, dependency or relationship, age, information defect, the patient's death, families' incorrect education, decision-making at the end-of-life stage, lack of coping skills, and diagnosis of the patient's condition, and the type of ICU needed.<sup>[31,45,48]</sup> These factors can predispose the formation and occurrence of secondary disorders; inadequate rest and exercise are common risk factors for health in families with the symptoms of stress and depression.<sup>[43]</sup> Families with higher levels of stress will also be more likely to develop PICS-F.<sup>[18,31]</sup> Accordingly, female family members of a younger age or with lower education will experience more psychological and physical symptoms. In addition, an appropriate relationship between healthcare providers and family members and provision of the family with information on the course of the illness and the patient's condition in terms of survival will be effective in reducing psychological and physical symptoms. Identifying effective factors in the occurrence of FICUS will provide the essential and appropriate approach in designing tools that can provide a more accurate assessment of the concept.

This review acknowledges the fact that families are an integral part of the care and treatment process, and that their participation and collaboration in patient care are among the goals of holistic or comprehensive care and play a key role in improving the quality of care.<sup>[55]</sup> ICU admission of one family member will affect the physical and mental health of other family members. Differences in the range of reported symptoms and predictors indicate the inadequacy of a merely quantitative evaluation of these disorders. The combination of quantitative and qualitative research can provide a broader view of the subject and lead to a better understanding of the symptoms; however, the majority of studies on the family and the experiences of ICU patients have cross-sectional and descriptive designs, and very few possess longitudinal designs.

A limitation of this study was that language limitation for the selection of studies made the authors select only the research resources in Farsi and English. Therefore, it was not possible to study the concept and its symptoms in other cultures.

## Conclusion

The family plays an important role in the process of treatment and care; however, various challenges occur which result in inconsistency in reasoning and improper decision-making. As FICUS is not accurately defined, the symptoms and the interventions have not been investigated in a specialized manner. The ambiguity of definitions and the inadequacy of measurements make the discussion of FICUS problematic. This integrative literature review provides an initial framework for defining FICUS and conducting further research on FICUS. Further research is needed to explore the concept of FICUS in the health context.

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## Conflicts of interest

Nothing to declare.

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