

A DNP PROJECT

Families' Experiences with an Adult Family Member in
a Critical Care Area: A qualitative systematic review

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DATE: April 17th, 2019

Review title

Qualitative Evidence on Families' Experiences with an Adult Family Member in a Critical Care Area: A systematic review

Reviewers

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Abstract

Background: Having a family member in the critical care unit is a challenging experience. The needs of families whose relatives are in a critical care unit are often poorly understood, underappreciated and ignored in the daily operations of the complex machineries that are integral to fully functioning healthcare environments.

Objectives: The purpose of this review was to understand and illuminate the total experience of critical care families and to use this information to generate recommendations for best practices, as an anticipated outcome.

Method: The method used was a systematic review of qualitative studies involving family members of ICU patients. The standard 3-step search strategy of JBI was used to find eligible studies. These were then screened by title, abstract and full review for relevance. Critical appraisal was performed by two reviewers working independently using the JBI MASTARI critical appraisal tools. Data were extracted by two reviewers working independently using a *de novo* tool designed for this review.

Data Analysis: A meta-synthesis of qualitative research findings using the JBI QARI program was done. This involved the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings (Level 1 findings), rating them according to their quality, and categorizing these findings based on similarity in meaning (Level 2 findings) to produce a single comprehensive set of synthesized findings (Level 3 findings), which can be used as a basis for evidence-based practice.

Findings: From 407 findings and 24 categories, three themes emerged: 1) Behind the Façade; 2) Balancing the Chaos; 3) Conquering the Alien Situation. This systematic review revealed that family members of patients in the ICU harbor feelings of isolation, helplessness, and anxiety and that accurate and timely information served as an antidote.

Evidence Transfer: An infographic for staff members was developed based on the findings.

Key words: intensive care critical care critically ill and family relative, needs, perceptions, experiences family members; families; relatives.

Summary of Findings

Systematic Review Title: Qualitative Evidence on Families' Experiences with an Adult Family Member in a Critical Care Area: A systematic review				
Participants: Family members with an adult family member who is a patient in a general critical care unit or intensive care unit or specialized critical care areas.				
Phenomena of Interest: The experiences, thoughts, feelings, opinions and expressed needs of family members with an adult family member in a critical care area.				
Context: Critical care area or intensive care unit				
Synthesized finding	Type of research	Dependability	Credibility	ConQual Score
Behind the Facade	Qualitative	High	High	High
Balancing the Chaos	Qualitative	High	High	High
Conquering the alien situation	Qualitative	High	High	High

Introduction

Background

The admission of a relative to an intensive care unit (ICU) or critical care area is a challenging, and often a debilitating experience for family members. The ICU can be intimidating for family members especially when they see their loved one connected to an array of IV lines, medication infusion pumps, and even an endotracheal tube. Every sound the cardiac monitor makes, and the IV pump that beeps, can be worrisome to an apprehensive family member unaware of the usual environment in the ICU.^{1,2} In some instances, the family member may be heavily sedated and unaware of their presence.² Unfortunately, the person who they love and adore and was relatively healthy prior to admission, is no longer recognizable.^{42,49} The fragility of the patient's condition left family members frightened because the recovery from illness and restoration of health seem grim.³ Consequentially, family members often suffered from depression, frustration, and guilt.³ They also suffered from denial, panic, or even debilitating physical symptoms.^{4,5}

Research studies have been performed to examine the experiences of family members of patients admitted to the ICU. Findings have been consistent across the studies: Need for consistent, and honest information^{1,3,5-13}, be in close proximity to the patient^{1,6,9,10,14-20}, overwhelmed with feeling of fear and anxiety^{1,2,8,14,18,21-26}, cultural traditions and religion^{6,11,18,20,27-29}, participation in caregiving^{1,5,6,10,14,23,25,30-32}, and receiving emotional support from family and friends.^{1,2,16,23,27,29} The Institute of Medicine (IOM) recommended that healthcare delivery systems become more patient-centered.³³ IOM also recommended the following: 1. Patients and families need to be kept informed and actively involved in decision-making 2. Healthcare delivery systems should provide comfort and emotional support to patients as well as their family members.³³ Despite these recommendations, the welfare of the critically-ill patient took precedence over the needs of the family. As a result, family members hid behind a façade of calmness but often felt isolated²⁴ and harbored feelings of trepidation.^{2,13,25,34-37}

Family members are pivotal to the patient experience and often share in decision-making, provide medical history, and offer a sense of security to the loved one. Moreover, the presence of family members in an ICU setting resulted in decreased levels of anxiety and increased levels of comfort for the critically-ill patient.^{38,39} Families who were integrated into the plan of care for the patient resulted in improved patient outcomes.^{40,41} While there is general consensus that involving families in the care process is essential and that such involvement may have a positive effect on both the family and the patient, the ways in which to accomplish this is not entirely clear. In fact, some studies have reported that family members are considered a burden by staff who must juggle the emotional needs of families and the emotional and physical needs of the patient simultaneously.⁴² In addition, the nurses excluded the family from caregiving because they felt the family did not have the skill set necessary to perform certain tasks.⁴³ For example, there was a study performed by Hupcey⁴¹ revealed that nurses prohibited the family from participating in patient care because they felt "*some of the family members are unfit and unsafe*" (p. 69). Consequentially, families became fearful that they may harm the patient and thus, refrained from the caretaking role.⁴¹ Prohibiting the family from participating in caretaking contributed to added stress and uneasiness.^{7,9,15,25,32,43-45}

Families felt that staff members often communicated conflicting messages regarding visitation. For example, Soderstrom et al.,²¹ reported that some families experienced a need to "crack the code" (p. 710) of implied messages. For example, when the nurse remarked, "*You can visit the patient whenever you want*" the implied and unspoken message was "as long as you do not disturb us in our work" (p. 710). Families who were able to decode staff messages felt satisfied and well treated by the health-care team during the critical care stay. In contrast, those family members who were unable to do so reported feelings of isolation and mistreatment.¹⁷ The findings of this study show that effective communication was an important mediator in family satisfaction.

Qualitative analysis can capture the human experience and give insight on the intangibles that cannot be measured by quantitative research. Nonetheless, many studies executed have examined the experiences of family members individually, but not in a systematic fashion, to embody the experiences of family members across similar studies. Hence, the purpose of this qualitative systematic review is to examine the experiences of family members of patients admitted in a critical care area to generate findings that will add to the body of existing knowledge, influence practice change, and policy development. The results of this review will demonstrate how incorporating the family in the plan of care for the critically-ill patient will reduce family stress, promote healthy coping mechanisms and effective communication, foster a trusting relationship with health care providers, and improve patient outcomes.

Objective

The purpose of this review is to understand and illuminate the total experience of critical care families and to use this information to generate recommendations for best practices. As such, this review synthesized available knowledge about family experiences in critical care areas so that conclusions could be drawn that are directly relevant to practice and provide an understanding of how family members perceive and articulate these experiences. More specifically, the review sought to:

- Identify the ways in which the experiences of having a family member in a critical care area shape their perceptions;
- Examine what it is like to have a family member in a critical care area in order to implement best practice in the care of families;
- Describe and recommend best practice specific to identified needs of critical care families.

Inclusion criteria

Types of participants

The review considered the experiences of family members with an adult family member who is a patient in a general critical care unit or intensive care unit or specialized critical care areas such as: burn units, trauma units, coronary care units, neurosurgical intensive care units (herein referred to as critical care areas). Participants were family members.

Types of intervention(s)

Phenomena of interest

This component of the review considered the following phenomena of interest: The experiences, thoughts, feelings, opinions and expressed needs of family members with an adult family member in a critical care area. This could take the form of addressing the behavior of families.

Types of outcomes

Outcomes of interest are closely connected to families' experiences of adult family members who are patients in critical care areas. These outcomes may be positive or negative, as expressed by family.

Types of studies

This review considered English language qualitative studies written during the period 1970-2018, are interpretive in nature, and draw on the experiences of families with an adult family member who is a patient in a critical care area. Research on family members of the critically ill began to be published during the mid-1970s. Qualitative studies included: phenomenology, grounded theory, narrative, ethnographic or cultural studies, or anthropology, etc. In the absence of research studies, other texts such as opinion papers, commentaries and reports were to be considered in a narrative summary.

Search strategy

The search strategy aimed to find both published and unpublished studies. A three-step search strategy was utilized in each component of this review. Firstly, an initial limited search of MEDLINE and CINAHL (including PreCINAHL) was undertaken followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second search using all identified keywords and index terms was then undertaken. Thirdly, the reference lists of all identified reports and articles were searched for additional studies. Also searched were:

PubMed

MEDLINE

HealthStar

ScienceDirect

Dissertation Abstracts International/Digital Dissertations

DARE

PsycINFO

BioMedCentral

TRIP (Turning Research into Practice)

PsycARTICLES

Psychology and Behavioural Sciences Collection

ISI Current Contents
Science.gov
Web of Science/Web of Knowledge
Scirus.com website
Sociological Abstracts

As the MeSH heading "qualitative research" in MEDLINE was only introduced in 1993, this term was not used for pre-1993 citations. Rather, all abstracts were reviewed to determine if studies met qualitative study inclusion criteria. Furthermore, author searching was conducted by searching each database for the names of authors of relevant reports to ascertain if they published other or similar work on the topic of interest. Journals devoted to critical care issues, such as *Journal of Advanced Nursing*, *Dimensions in Critical Care*, *The Journal of Critical Care*, *Critical Care Nursing Quarterly*, *Critical Care Medicine*, and *Heart and Lung*, were hand-searched to be as complete as possible in finding studies regarding critical care.

Key words or phrases included: intensive care critical care critically ill and family relative, needs, perceptions, experiences family members; families; relatives.

The search for unpublished studies or grey literature included a search of Google Scholar (Advanced) and studies' footnotes. A more extensive search for grey literature was not necessary as enough primary studies were identified for inclusion.

Method of critical appraisal

The titles and abstracts of articles identified from the search were reviewed independently by two reviewers for appropriateness. Those deemed appropriate were retrieved in full text and re-reviewed against the inclusion criteria. Papers meeting inclusion criteria were assessed by two independent reviewers for methodological validity prior to inclusion in the review using the Joanna Briggs Institute Qualitative Appraisal and Review Instrument (JBI-QARI) (Appendix I). All studies were appraised using the full criteria, however, papers not meeting criterion 2 (there is congruity between the research methodology and the research question or objectives) and criterion 4 (There is congruity between the research methodology and the representation of the analysis of data) were excluded. Any disagreements that arose between the reviewers were resolved through discussion with a third reviewer.

Data extraction

Data was extracted from papers included in the review using the standardized data extraction tool from the Joanna Briggs Institute: JBI QARI (see Appendix II).

Data synthesis

Qualitative research findings were pooled using the JBI QARI program. This involved the aggregation or synthesis of findings to generate a set of statements that represent that

aggregation, through assembling the findings (Level 1 findings), rating them according to their quality, and categorizing these findings on the basis of similarity in meaning (Level 2 findings). These categories were then subjected to a metasynthesis in order to produce a single comprehensive set of synthesized findings (Level 3 findings), which can be used as a basis for evidence-based practice.

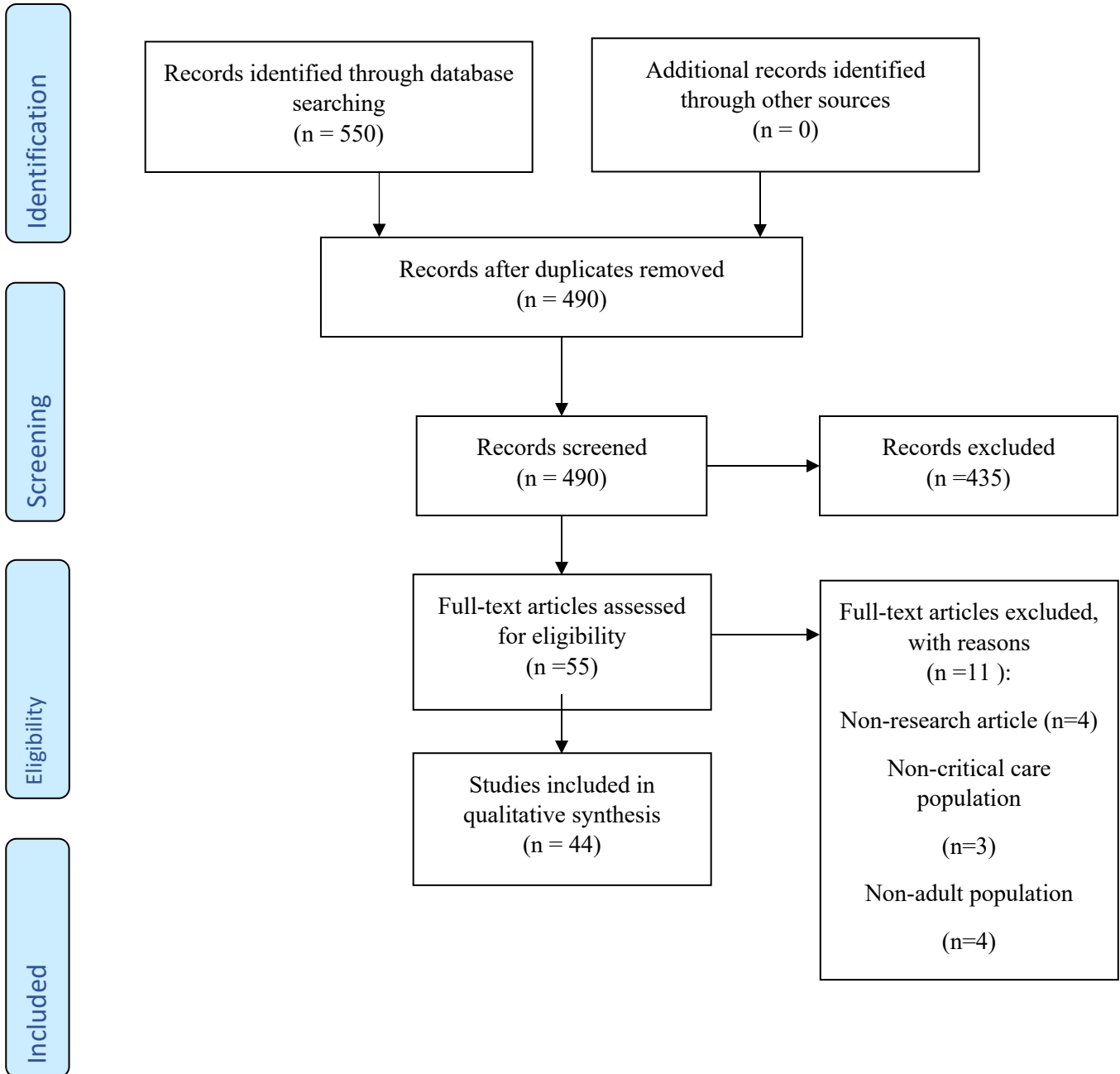
Results

Description of included studies

Figure 1 presents the PRISMA diagram of included and excluded studies. There were five hundred and fifty studies identified from the search strategy and a total of four hundred and ninety appeared eligible for inclusion after duplicates were removed. All were screened for inclusion based on title and abstract and four hundred and thirty-five were excluded. Fifty-five articles were assessed for inclusion through full text review using inclusion and exclusion criteria. Eleven articles were then excluded after full text review leaving forty-four studies that were appraised for methodological quality using the JBI-QARI assessment of methodological quality tool (Appendix III). All were found to be worthy of inclusion.



PRISMA Flow Diagram



Methodological quality

A total of forty-four articles were reviewed for methodological quality. All studies rated positively for questions related to congruity between research methodology and research question, research methodology and methods, methodology and representation of the analysis of data, research methodology and interpretation of results, ethical approval, conclusion drawn, and voices represented. The final assessment table for critical appraisal of included studies is presented in Table 1.

Table 1

Methodological Quality of Included Studies

[illegible]

[illegible]

Description of included studies

This review is comprised 44 qualitative articles regarding the perception of 1585 family members, aged 16 to 79 years, about their experiences when an adult member of the family is a patient in a critical care area. The critical care areas varied among general intensive care units (30), neurological intensive care units (5), medical-surgical intensive care units (4), and surgical intensive care units (2). Family members represented 13 countries, including the United States (15),^{2,5,7,9,10,19,23,24,28,29,31,32,35,43,44,47,48} Sweden (6),^{1,15,21,45,46,49} Australia (3),^{13,16,51} England (3),^{14,20,26} Canada (2),^{17,34} Norway (2),^{25,27} Iran (2),^{3,8} Greece (2),^{11,18} Belgium (2),^{12,37,50} Saudi Arabia (1),⁶ Denmark (1),³⁰ Hong Kong (1),²² and Brazil (1).³⁶ The 44 included studies were published from 1989 to 2018.

Research designs of the included studies included qualitative descriptive,^{7,22} narrative approach,¹ grounded theory,^{26,43,47} hermeneutical,^{49,51} and content analysis.^{8,44} These studies used the following data collection methods: —semi structured interviews,^{3,6,9,10,16,18,19,23,29} in-depth interviews,^{12-14,27,28,30,48,50} focus groups,² were used phenomenology,^{5,15,24,25,31,34,36,46}. The sample size ranged from 5²⁷ to 880¹⁷ with the mean sample size of 48 participants for this review. As presented in Table 2, three syntheses emerged from 24 categories and 407 findings.

Table 2: Findings-Categories-Synthesized Name and Definition

# of Findings	Categories	Synthesis
18	Advocacy for Loved Ones	Behind the Façade
21	Learning the Ropes	
64	Close Vigilance	
9	Families Excluded and Ignored	
23	Kept in the Dark	
10	Façade of Calmness	
20	Suspended Living	
28	Enduring Uncertainty	Balancing the Chaos
36	Engulfed by Emotions	
7	Exhaustion Sets In	
16	Magnified Helplessness	
6	Soloing	
11	Never the Same Again	Conquering the Alien Situation
5	Bringing Identity to Life	
14	Confidence Brings Comfort	
9	Connectedness through Caretaking	
14	Deep Family Bonds	
14	Holding True to Cultural Traditions	
8	Hope as an Antidote	
41	Information as an Antidote	
2	Managing Grief	
22	Social Support as an Antidote	
3	Experience as an Antidote	
5	Blaming the Loved One	
1	Guilt	
Total Findings=	Total Categories=	

Synthesized Finding 1: Behind the Façade

This meta-synthesis was created from seven categories and 166 findings.

For family, the crisis of acute illness suspends normal living. Energy and attention are directed toward advocating for their loved one(s). This close vigilance requires family to be present with

the patient. They actively work to build relationships with staff and learn hospital routines to enhance the likelihood that will be acknowledged by the health care team. They hide their concerns behind a façade of calmness so they can be positive when interacting with the patient and others. This calmness may not be seen as a front and the emotional needs of families may be missed by staff. Families report stress associated with being excluded and ignored by staff and intense anxiety occurs when they are “kept in the dark,” an experience that is felt as they fail to receive timely, comprehensive, and consistent information.

Category 1: Advocacy for Loved Ones

15 Findings

Families assume an advocacy role to protect both the patient as well as other family members. This entails being with the patient, assessing the care provided and taking measure when gaps in care occur, filtering information, breaking bad news gently, providing emotional support, facilitating communication, managing the environment to promote a calm atmosphere and encouraging others to maintain their well-being and normal routines. Staff was not always supportive of the family advocacy role and being chided for their advocacy brought additional stress.

Category 2: Close Vigilance

64 Findings

Families expressed a strong need to be near the critically ill family member as vigilant attendance was seen as the main form of support for both the patient and family. Vigilant presence made patients feel more secure, gave them courage, and fostered a sense of connection. For families, close vigilance gave an opportunity to observe, listen, and ask questions. Close watchfulness allowed family members to be on guard and assume the advocate role.

Category 3: Façade of Calmness

10 Findings

Family expends large amounts of energy enduring the stressful situation and hiding their emotions in a façade of calmness so to be positive to the patient and other family members. Staff often fail to recognize the calmness as a front and may not be aware of the emotional needs of the family.

Category 4: Family Excluded and Ignored

9 Findings

An added stress (distress) for families was not receiving support and understandable information from nurses. Family were sometimes excluded from discussions about the patient’s condition.

Category 5: Kept in the Dark

23 Findings

Not knowing caused intense anxiety and distress yet families often were kept in the dark. They report endless waiting for information and ultimately receiving inconsistent, insufficient, and variable quality of information leaving them unsure of what was real. Paradoxically, families may refrain from asking questions as they do not want to negatively affect the care provided.

Category 6: Learning the Ropes

21 Findings

Families actively work to build relationships with staff and learn hospital procedures and routines in order to make sense of the health crisis and care and to facilitate inclusion in team approach. Over time family become more competent in their assessment of the environment, the medical team, and the patient.

Category 7: Suspended Living

20 Findings

Family and personal life was on hold and the nucleus of existence became the patient. All energy and attention were directed to waiting, such as waiting for information, waiting for visiting hours, waiting for the nightmare to end, waiting for the outcome. Waiting required a moment to moment or day-to-day focus and timeliness were blurred. The uncertainty associated with waiting was very stressful.

Synthesized Finding 2: Balancing the Chaos

This meta-synthesis was created from six categories and 103 findings.

Family must endure the painful uncertainty associated with waiting out the outcome of physiologic instability while often their major form of support is no longer available and they must manage alone through unknown waters. During this time, families experience a rollercoaster of intense emotions depending on the patient's condition at the moment. They feel a loss of control and helplessness as they are powerless to impact the physiologic condition of their loved one. While they manage their emotions associated with changing instability and the realization that the person may never be the same again, their energy is focused on close vigilance and advocacy to the exclusions of care of self. This can take a physical and emotional toll and family needs to be encouraged to take steps to protect and distract themselves from the intense situation so they have the energy to endure what lies ahead.

Category 1: Enduring Uncertainty

28 Findings

A major challenge in enduring the uncertainty of the situation and waiting to see what the outcome will be. Family waits for information but the reassurance brought by information is short lived due to the changing nature of the patient's condition.

Category 2: Engulfed by Emotions

36 Findings

Families experience a rollercoaster of intense emotions that accompanies the ups and downs of the patient's condition. Coping with the chaos of emotions from shock, fear, and anxiety to confusion, anger and worry is important as the family wants to "balance" their emotions so they can attend the needs of the family.

Category 3: Exhaustion Sets In

7 Findings

The stress of keeping oneself going and protecting the patient and other family members is demanding and begins to take a physical and emotional toll. If family does not take steps to protect and distract themselves from the intense situation, exhaustion ultimately sets in a point they are forced to take some care of themselves.

Category 4: Magnified Helplessness

16 Findings

Overwhelming emotions and uncertainty of outcomes creates a sense of loss of control and helplessness. This is further magnified by vacillating symptoms, ambiguous and changing information and communication with physicians and nurses and unexpected events.

Category 5: Never the Same Again

11 Findings

As families receive more information, there is growing awareness of future suffering and challenges for both the patient and family. At this time, family needs practical physical and emotional support.

Category 6: Soloing

6 Findings

Separated from their loved one due to critical illness, spouses found themselves alone and responsible for everything that had previously been shared.

Synthesized Finding 3: Conquering the Alien Situation

This meta-synthesis was created from ten categories and 129 findings.

Staff can support family to endure the stress of the situation by encouraging family to participate in caretaking tasks, encouraging reminiscence which personalizes care by bringing identity to

life, communicating with hope, and providing information in a timely, empathetically delivered, straightforward manner. As family gains confidence in staff, they are comforted and supported. Additional strength was found in prior coping experiences, the support from family and friends, spirituality and holding true to cultural traditions that have meaning to the family. An outcome of the shared experience is deepening of family bonds with a feeling of enhanced closeness and appreciation.

Category 1: Bringing Identity to Life

5 Findings

Belongings from home and insight into the patient's accomplishments and life help nurses to provide a personalized care that is valued by families. Reminiscence helps to bring temporary emotional relief.

Category 2: Confidence Brings Comfort

14 Findings

A supportive presence of knowledgeable, competent nurses, and a caring approach brought comfort and support and sense of safety to family.

Category 3: Connectedness through Caretaking

9 Findings

Caretaking is a central role of families and they are eager to help. The ability to be helpful and assist in caretaking tasks maintains the family/patient connection and brings a sense of participation and meaningfulness.

Category 4: Deep Family Bonds

14 Findings

The shared experience of living through critical illness bring families closer together with a greater sense of appreciation for each other. The resulting family cooperation with a reallocation of role responsibilities is important in managing the stress of the situation.

Category 5: Experience as an Antidote

3 Findings

Families with prior experience of hospitalization or knowledge of medicine were better able to cope with the stress and took better care of themselves.

Category 6: Holding True to Cultural Traditions

14 Findings

Cultural traditions defined the caregiver and information dissemination role of families as well as the meaning/interpretation of the cause of illness and healing rituals.

Category 7: Hope as an Antidote

8 Findings

Hope is facilitated through confidence in medical personnel, presence, and optimistic communication. Those with hope were more able to participate as caregivers.

Category 8: Information as an Antidote

41 Findings

Information was an antidote for fear of the unknown and the confusion present in the alien situation. Family searched for new information from different health care providers as well as educational and online resources. Waiting for information was difficult and hope was maintained by gathering and receiving empathically delivered honest, straightforward, and detailed information whether it was good or bad in nature.

Category 9: Managing Grief

2 Findings

Expressions of grief and reminiscence bring temporary emotional relief

Category 10: Social Support as an Antidote

22 Findings

Social support is the form of spiritual support, empathy from family and friends, and caring from and confidence in competence of health care providers in calming and comforting.

Discussion

This systematic review of qualitative evidence was undertaken to better understand the experiences of families when a family member is a patient in any type of critical care. Forty-four research papers were included in the review after a transparent search and inclusion process. The level of evidence, using ConQual was interpreted to be high. The three metasyntheses had high dependability ratings. This systematic review revealed that family members of patients in the ICU harbor feelings of worry, powerlessness, isolation, and that accurate, honest, and timely information served as an antidote.

Any admission to a critical care unit signals the fragility of human life. The daily emphasis shifts from day-to-day life, and planning the future, to survival and the corresponding desire for things to be ‘as they were’. Admission can take various forms across all age groups. However, the one constant factor is the need of the critical care patient to be supported through a life-threatening

state of ill health. Often, the patient is rendered unconscious by illness, accident, or sedative agents and may be unaware of their fragile and critical state. The people who are always aware and serve as the patient advocate are the patient's family members.

Metasynthesis 1 addressed the façade of calmness that family members hide behind when faced with the crisis of an acute illness. On admission to the ICU, family members are often overwhelmed with feelings of worry and shock when they see their loved one in the hospital bed. Oftentimes, family members associate the ICU with death and dying. Hence, during this critical time, some family members want to be provided information only on the current status of the patient rather than the overall prognosis in part because they are in a state of frenzy and cannot process too much news at once.^{13,14,26} Other family members want to be given honest information regarding the patient's condition that is not "*sugar-coated*" so that, they can psychologically prepare for the worst.^{1,5,6,8,9,12,13} During this time, there was a prolonged period of waiting: waiting for information regarding the patient's status, waiting to visit the patient, and waiting to obtain news if the patient will survive his/her ailment. The extended waiting worsened family stress and anticipatory grief.

Families often appeared to be coping effectively in part because they did not want to express negative emotions in front of the patient.^{18,19,21,29,50} For example, in a study performed by Hupcey⁴³ family member explained how she "*ran off to the bathroom to cry but always emerged with a smile on her face*" (p. 259). In the same study, a wife explained "*I kept it a lot inside. You know. I didn't want to show him that I was upset. I tried to remain very strong*" (p. 259). In another study performed by Kutash and Northrop¹⁹ a family member stated "*When in that room I'm fine. I hold it together. But when I go through the door, I'm not fine anymore*" (p. 386). Interestingly, the implicit message interpreted by the family is that the staff is primarily there to attend to the patient's needs and that their needs are not as important. If by chance, the family needed assistance, they would seek it somewhere else.²¹ Family members would be careful to adhere to the ICU rules, only ask questions about the patient's condition, and would stay in the room as much as possible because that way, they could receive continuous information.²¹ Consequentially, staff members would be oblivious to the needs of the family because they did not express their emotions openly. As a result, family members emotional needs were often unmet and unaddressed.

Families anticipated that nurses would readily answer their questions regarding their loved one. However, when their questions were left unanswered, families became more anxious and worried. For example, in a study executed by Hekmatpou et al.³ a brother explained "*We want to know why they are using this machine and what the signs in the monitor above her head mean, but they just tell us, 'Get out! We have lots of work to do here'*" (p. 120). Nonetheless, family members felt excluded from discussions regarding plan of care for the patient. In the study performed by Henrich et al.¹⁷ family members stated that the physicians would do the following: ask them to step out of the room when they discussed the patient's condition, they would speak among themselves outside the patient's room about the plan of care for the patient, and they would even discuss the patient's condition in their presence but not include them in the conversation. Conversely, in a study performed by Frivold et al.³² a family member who was included in rounds for her loved one explained "*I could just sit there watching them working on*

my husband . . . I still was numbed by fear, but still I was impressed by these people, six or seven of them, they all seemed to be so confident” (p. 237). Physicians should permit the family to participate in discussions regarding the plan of care for the patient because it helps reduce stress, helps the family build confidence in the healthcare team, and reduces confusion. For these reasons, nurses need to address any concerns or questions the family may have.

Family members describe how they dreaded the process of waiting. Waiting was difficult as it fueled anxiety and stress. In a study implemented by Henrich et al.¹⁷ families spent a prolonged period of time waiting in the waiting room to see their loved ones in part because there was a two-hour discrepancy between the time they were told to wait and the actual time they waited. The family described the experience and stated *“I am still waiting outside the ICU to come in feeling like I am going to be sick because I do not know what they are doing or why it is taking so long”* (p. 1003). Family members also described how they often waited for information regarding the patient’s diagnosis, how the patient was responded to treatment, and the results of blood work and procedures which took an emotional toll on them.^{1,5,10,17,23,30,34}

Families often felt they were left in the dark regarding the patient’s condition.^{2,29,44} In a study performed by Jamerson et al.² a participant stated, *“I just felt in the dark. I really didn’t know anything and the fear of not knowing was worse I think than knowing, than preparing yourself to deal with it”* (p. 471). In a study executed by Hansen et al.⁴⁴ family described how they felt oblivious to the patient’s status and stated *“I wish we would speak more often to the doctor. They do not come in [to the patient’s room] very often.”* (p. 450). Families not kept in the loop regarding their loved one’s state of health were often terrified and apprehensive.

Families frequently received inconsistent information from the healthcare team which caused confusion and even conflict within the family.^{3,7,8,10,13} For instance, a study was implemented by Bond et al.⁷ and participant described how family members received conflicting information from different providers and stated *“when we came together as a family, it was very confusing and very problematic; we almost started fighting”* (p. 67). A study was executed by Hekmatpou et al.³ and a participant stated *“Each nurse expresses a different opinion. One says that the patient has become better, while the other one believes that he has not improved. This made us more worried”* (p. 120). The discord between the healthcare team could arise from nurses and physicians not communicating with one another and thus, the family members receive conflicting information regarding their loved ones.³ Effective communication among the health care team will reduce misperception and improve the family experience in the ICU.

Critical care areas are dynamic, potentially life-saving environments containing some of the most advanced technology available to nurses and medical staff. Family members entering a critical care are bombarded by the huge array of new sensory stimuli and are typically in a state of fear and shock. They actively work to build positive relationships with the staff and attempt to learn hospital routines and policies. They do this in an attempt to be acknowledged by staff in the hopes that they are not ignored and receive the information they need to fully understand what is happening with the patient.^{5,17,26,44,48,50} Moreover, family members felt the media gave them unrealistic expectations regarding the ICU experience and thus, families sometimes resorted to this for clarity. For example, a study was performed by Hughes et al.²⁶ and a participant

explained how he thought the ICU was disorganized and stated *“I have never been in intensive care before, but I think if you had asked me prior to this what was it like, I think I would have thought people running around like blue-arsed flies”* (p. 26). Hospitals should have pamphlets (located in the waiting area), or videos explaining what the ICU experience may be so that family members have an accurate description for reference. This will help to alleviate stress and anxiety.

Families often served as an advocate for their loved ones by ensuring they received appropriate care, filtered information to the patient, and provided emotional support.^{2,5,9,10,45,47,50} For example, in a study executed by Nelms⁴⁸ a participant stated, *“My sister felt like this watch dog . . . I think she feels like she has to take care of everything and keep an eye on everything, on the nurses so that they are not screwing up”* (p. 469). The family wanted to stay at the bedside to vigilantly observe the care provided. For instance, in a study performed by Johansson et al.⁴⁵ a family member stated *“I felt that I should watch over him to ensure that everything was done properly. So I spent as much time as possible there in order to check up on everything”* (p. 293). Family members not only provided emotional support to their critically-ill loved one, but also to other family members by breaking bad news to them gently or protecting them from additional stress or worry. For example, in a study performed by Fontana²⁴ a husband with three children stated, *“For the kids, I always tried to be positive. I absolutely insisted on focusing on any positive part of the process that I could find for the kids to be able to have hope that she would be okay”* (p. 227). Findings from this study show that families protect the interests and well-being of the patients as well as other family members in a time of crises.

A consistent finding in this review revealed the overwhelming need for the family to be in close proximity to the patient because it helped to ease apprehension, stress, and allowed them to effectively cope.^{1,6,9-11,14-17,19,20,23,28,29} Families often felt uneasy leaving the bedside due to the patient's unstable condition. For example, in a study performed by Nelms¹⁰ the mother of a twenty-three-year-old daughter said *“It's hard to explain the feeling . . . I just have to be here. I just have to I think once she is extubated I will be able to go, but right now I need to be here”* (p. 470). Moreover, the hospital lacked the facilities to accommodate family members outside of the ICU.^{3,44} One family member expressed his dissatisfaction with the lack of waiting rooms saying *“There is no place to sit down. We have to sit on the dirty floor. There are no facilities for us”*.³ In addition, if the hospitals did have a waiting room, it was often unclean and not hospitable.^{17,19} For instance, in a study performed by Henrich¹⁷ participants complained that the waiting rooms were often *“dirty, unwelcoming/dreary, uncomfortable, and too small”* (p. 1003). Moreover, restricted visiting hours prevented families from spending quality time with the patient. Some family members lived a far distance from the hospital and by the time they did arrive to see their loved one, visiting hours were almost over. One family member stated, *“The visiting time was neither sufficient nor appropriate; we come from a very far place. Due to the traffic sometimes we arrive towards the end of the visit, we stay for only five to ten minutes then the security asks us to leave”* (p. 140).⁶ There were also instances where the visiting hours were not the same everyday which caused added pressure and frustration for the family. Plowfield⁴⁸ performed a study where the participant complained about the variability of the visiting hours. After traveling for two hours to get to the hospital, he stated *“they pretty much implied that they weren't going to let us even see her even to look at her nothing”* (p. 234). Nonetheless, in a study performed by Nelms,¹⁰ family members were called to come back to the

hospital to see their unstable family member. When the family arrived, the nurse told them “*only two at a time*” (p. 474). Flexible and consistent visiting hours allow for families to provide emotional support for the patient, strengthens the family’s ability to cope, and gives the family the opportunity to speak with the healthcare team regarding the patient’s status.⁶ Moreover, hospitals need to provide the families of patients admitted to the ICU with a clean, and welcoming waiting room, and a place to stay the night, if necessary, to meet their physical needs.

Family members spend a great deal of time at the bedside providing emotional and physical support to their loved ones that they often neglect the needs of their family and personal lives.^{1,3,16,23,28} It is particularly difficult for family members to balance spending quality time with their children and the hospitalized loved one. In a study executed by McKiernan et al.²⁸ a participant stated “*It’s so hard when you’ve got families, jobs, kids...trying to be here as well...you feel you have to be up here, you want to be up here and yet you can’t be here all the time*” (p. 258). Some families even faced financial strain from hospital expenses, reduced income, and a higher cost of living.²⁸ It is essential that families find a balance to manage their personal, and family life along with providing support to their critically-ill family member.

Metasynthesis 2 found that families use a variety of methods to balance chaos. Families must endure the painful uncertainty associated with waiting out the outcome of physiologic instability.

Critical illness necessitating admission to a critical care unit often occurs without warning. Families of those admitted to these areas are left feeling vulnerable and helpless with no clear knowledge of what to expect.^{9,16,22-24,29,30,34,45,48} Findings from this review show that the fear of not knowing is worse than knowing. The uncertainty of whether the patient will live or die causes the family to be consumed with doubt and apprehension. Nonetheless, in a study performed by Agard et al.³⁰ a participant stated “*I don’t think I really understand how sick he is... Well maybe I do, but I can’t deal with it right now. Sometimes it comes to me and my heart starts pounding and I feel like I am going to faint*” (p. 173). In another study performed by Nelms¹⁰ a family member described her feelings of ambiguity and stated “*The illness is scary because that person might not be there . . . the idea of them being snatched from you . . . that’s really hard*”; “*We didn’t think she would make it through the night*” (p. 468). Healthcare providers can help families endure uncertainty by providing them with as much information as possible to help them cope with stress and will set the foundation for a trusting relationship with the staff.

Family members were consumed with feelings of sadness, uneasiness, trepidation, guilt, and frustration due to their loved one’s ICU admission.^{1,2,8,14,18,21-26} Initially, many family members experience shock upon notification of their loved one’s admission to the ICU.¹⁴ At this critical time, family members often hear the healthcare team speaking to them but because their mind was in a frenzy, they could not listen. For example, in a study performed by Fontana²⁴ a family member described how she felt upon notification of her husband’s ICU admission. She stated “*It was like I was numb. I was like, I don’t believe this. I didn’t have normal reactions. I can’t say I feared anything. I just had a total shock reaction, sitting there listening to a bunch of strangers talk to me*” (p. 225). In the same study, one participant described how she ultimately was placed on anxiety medication and suffered from depression once her husband was discharged home due

to her inability to cope. Healthcare providers can help alleviate the added pressure and worry families face by being empathetic, providing the information requested regarding the patient's status, and ensuring the family member is equipped to care for their loved one post discharge.

Caring for a critically ill family member admitted to a critical care unit can be emotionally and physically exhausting.^{1,10,22-24,48} Energy is utilized due to traveling long distances to the hospital, long periods of waiting, and the demands of family life at home. All of the family members' efforts are directed towards restoring their loved one's health that they often neglect themselves by not eating, and sleeping which resulted in decreased strength and severe fatigue. For instance, in a study executed by Engstrom and Soderberg¹ a participant explained how he didn't have the strength to take the dishes out of the dishwasher. He stated, "*The sink was completely full before you could manage to get up and put it in the dishwasher; we have a dishwasher you know, so it was only a matter of putting it in the dishwasher, but not even that was possible*" (p. 303). Healthcare providers can help reduce the family members' fatigue by reducing waiting time outside the ICU and allowing them to stay at the patient's bedside as long as possible.

Families felt helpless in their efforts to nurture their loved one back to health.^{10,14,16,23,24,29,43,48} They wanted to help the patient in any way possible but was unsure how to and thus, resorted to close vigilance instead. Nonetheless, the machinery and the ICU environment can be frightening to family members and thus, some refrained from even touching the patient. For instance, in a study that was performed by Agard et al.³⁰ a family member stated "*I missed touching him and being here by his side. Of course I could have asked the nurses if there was something I could do, but somehow I just never really got to that point*" (p. 174). In another example, a study was performed by Ruppert²⁹ a family member explained how she felt powerless in her ability to improve her loved one's health. She stated "*You really feel helpless that there is nothing you can do. Pat their hand or hold their hand or whatever but here is really nothing you can do, and that is very frustrating too*" (p. 84). Loss of control can fuel frustration and fear. Hence, the healthcare team should allow the family to participate in caregiving, educate the family on the ICU monitors and IV pumps, and be empathetic and compassionate to their needs.

There are some critically-ill patients whose condition improves and they are able to return home. However, some do not return in their previous state and are left disabled or unable to completely care for themselves. Families often have a difficult time adjusting to who the patient has become after their ICU admission. Nonetheless, in a study implemented by McKiernan et al.²⁸ a family member stated "*Its heartbreaking if you think that he can hear us but not be able to show it. And the brain works everything and they know that is severely damaged...for a man that was so lively...to see him like this is really terrible*" (p. 258). The focus shifts to protecting what quality of life the patient is left with and thus, family members often reminisce on the memories of the patient prior to his/her illness and utilized that opportunity to gain the will-power to rebuild life.¹⁷ Moreover, a study performed by Fontana²⁴ a family member explained how he had to adjust to a new life. He stated "*You have to establish a new normal and you have to live with the fact that there is a new normal. You will never be the same. You are forever changed by it*" (p. 229). Healthcare providers can refer the family members to social work to help them as well as the patient, adapt to a new beginning.

Family members have to adapt to changes at home while their critically-ill loved one is hospitalized in the intensive care unit. Household responsibilities that were once shared, now became the responsibility of the family member. Nonetheless, in a study executed by Chan et al.²² a wife described her feelings after working long hours and having to visit her husband in the hospital: *"I desire my husband coming home and helping to share my burdens and responsibilities of home affairs"* (p. 189). Also, families felt lonely and isolated without their loved at home. A participant in the study performed by Hekmatpou et al.³ stated *"I have a strange feeling of loneliness. He used to support us and I do not know how to continue life without him. I feel I have been left alone in this world, without a support"* (p. 121). Family members come to the realization that the life they once shared with their loved one, has changed indefinitely.

Metasynthesis 3 found that families attempt to conquer this alien situation. Staff can support family to endure the stress of the situation by encouraging family to participate in caretaking tasks, encouraging reminiscence which personalizes care by bringing identity to life, communicating with hope, and providing information in a timely, empathetically delivered, straightforward manner. As family gains confidence in staff, they are comforted and supported. Additional strength was found in prior coping experiences, the support from family and friends, spirituality and holding true to cultural traditions that have meaning to the family. An outcome of the shared experience is deepening of family bonds with a feeling of enhanced closeness and appreciation. Protecting and meeting the patient's needs was family members' priority. Even though the admission had a significant impact on their quality of life personal physical and psychological distress, they considered their needs secondary to being devoted to patient's health and support.⁴⁸

Critically-ill patients are often unable to communicate with health-care providers or participate in plan of care decisions which leaves the responsibility to the family members.^{52,53} Family members often have first-hand insight into patients' preferences, emotional and physical responses, and can make important contributions to care decisions. Hence, family members brought in important personal items of the patient from home to encourage reminiscing which resulted in strengthening both the patient and family's coping mechanisms.^{1,9,29,44} For example, in a study performed by Engstrom and Soderberg¹ a family member who brought in her husband's favorite pillow stated, *"He also had a pillow of his own and they were not allowed to take it away because it's a special pillow ... that was an important thing"* (p. 302). Family members often brought in clothing, soap, and other personal items that were of value to the patient.⁹ Moreover, the nurses would develop interpersonal relationships with the family members in an effort to learn more about the patient to provide individualized patient-centered care.^{25,43} Findings from this review support the greater body of evidence that families should be integrated into the plan of care to help improve patient outcomes.

In this review, the family members were comforted by the nurses who provided compassionate and empathetic care and who displayed confidence and professionalism.^{2,5,10,14,20,28,38,50,51,53} Nonetheless, in a study was implemented by Coulter¹⁴ a relative described her perspective of care and stated *"But when you see the care and love, there is no other word for it; when they are*

wiping her eyes and putting drops in; cleaning her mouth” (p. 7). In addition, another study was performed by Jamerson et al.² where family member commented on the nursing care and stated “*They knew exactly what they were doing . . . Any type of procedure, I had no doubts that they knew what they were doing. It made us feel like she was in good care... I felt..., they were very competent*” (p. 472). The findings of this review show that family members associated confidence with caring and comfort. In addition, family members felt the patient was safe and secure in the hands of the nurses who demonstrated competency and confidence.

Families often felt helpless as they watched their loved one in a hospital bed connected to machinery they didn’t understand. In addition to feelings of powerlessness, families also felt a loss of control because of the uncertainty of recovery and the threat of death and dying. Moreover, families found comfort in caretaking, assisting in bathing, to even moistening the lips of their loved one.^{1,5,6,10,14,23,25,30-32} Nonetheless, a study was executed by Agard et al.³⁰ and a family member explained how she appreciated “*when a nurse would invite them to stay by the bed instructing them, for example how to wipe the patient’s face, moisten the patient’s lips, massage an arm, or read aloud from the paper*” (p. 174). In contrast, some family members were not allowed to participate in caregiving which ultimately caused apprehension. For example, a study was implemented by Al-Mutair et al.⁶ and a participant described how he was not permitted to care for his father. He stated “*If I’m given the choice, I would sit in front of him [father] all the time, feed him, take care of him, talk to him, read Qur’an for him: at least this will reassure me and reduces my anxiety*” (p. 141). Involving family in the caretaking role alleviates stress and fear and thus, improves patient outcomes.

Family members spend a tremendous amount of time in the hospital with their critically-ill loved one and thus, they often neglect the responsibilities of everyday life (washing the dishes, taking care of the children etc.).^{1,2,16,23,27,29} Moreover, family members seek support from family and friends during this critical time. As they endure the ICU experience, the family bond is strengthened, they protect each other from added stress, and they are empathetic with each other. This strengthened bond brings a sense of security to the family knowing, they can depend on each other. Moreover, in a study performed by Hoyer et al.²⁷ a family member explained “*In the first week after admission everyone was here (in the hospital) and we felt more secure being near to each other than being far away*” (p. 28). In another example, a study implemented by Burr¹⁶ a participant explained “*I knew the children would be fine because I can trust my friends and my family to look after them while I’m here [at the hospital]... they said don’t worry about anything at home*” (p. 166). Findings of this review reveal that families protect and support each other in times of crisis.

Family members resorted to cultural beliefs and traditions to help them cope with stress, and fear.^{6,11,18,20,27-29} Religion and spirituality strengthened their coping mechanisms and provided a sense of hope for the family. For instance, the study executed by Koukoulis et al.¹⁸ the family member stated “*These days (I believe in God) even more. In difficulties we are always looking for something to hold on, something to give us hope*” (p. 48). Also, there was a study performed by Hoyer et al.²⁷ where a family described how he personalized his wife’s care. He stated “*I bought an Indian God which my wife [the patient] is very fond of. I told the nurses that it would*

help to make her well” (p. 28). Health-care providers should encourage family members to integrate culture and religious beliefs into the care of the patient.

The fate of critically-ill patients is unknown. Nonetheless, families depend on the information from physicians regarding the patient’s condition to determine if ICU care is futile. They associate positivity with hope. For example, in a study implemented by Johansson and Hildingh⁴⁵ a family member explained how she kept a positive attitude in the midst of her crisis which resulted in renewed strength. She stated, *“I convinced myself that he would pull through. You have to have a positive attitude, how else would you get the strength to cope?... I also feel that I have emerged a much stronger person”* (p. 292). In a study performed by Fry et al.⁵ a family member described how she remained positive regarding her loved one’s recovery. She stated *“I have seen her much sicker than this. She is a tough person and she will pull through this, I know she will. We are not giving up.... I am thinking positive”* (p. 186). The findings from this study revealed that family members maintain hope for a positive patient outcome.^{5,6,14,16,23,45,48}

Families seek support from not only other family members or close friends, but from the healthcare team as well. Family members found comfort and security in the health-care providers who were attentive, respectful, maintained eye contact, and empathetic.^{5,8,25,45} Moreover, in a study executed by Johansson et al.⁴⁵ a family member described how responsibility and commitment equates to confidence. The participant stated *“The main thing, which is more important than anything else, is that the doctors act in a way that inspires trust in my son's treatment . . . then everything else is only of minor importance”* (p. 295). Family members who encounter attentive, altruistic, and accountable healthcare providers are satisfied with the care provided to their loved one.

Families relied on information regarding their critically-ill loved one’s condition to help ease apprehension and fear. A consistent finding in this review is the overwhelming need for families to obtain honest, and consistent information from healthcare providers concerning their loved ones.^{1,2,5-9,12-14,18,20-22,26,28,37} Families wanted to know what the prognosis was, whether good or bad, so that they can psychologically prepare for the worst. For example, a study was performed by Gaeni⁸ where a family member described how she received a call from the hospital informing her that her son was in an accident and the only information she needed to know was the truth regarding his status (if he was alive or if he passed away). She stated *“I went to the hospital and asked hospital guards, service men, nurses and doctors what had happened to my son, I just wanted them to tell me the truth whether he was alive or not?”* (p. 11). Moreover, a study was executed by Burr¹⁶ where a participant described how he wanted the information relayed to him straightforwardly regarding the status of his loved one. He stated *“Don’t sugarcoat! I can take it. Please give me some reality. If there is no hope, tell me there is no hope!”* (p. 67). In contrast, there are some family members who only wanted to know the current status of the patient. In a study implemented by Hughes et al.²⁶ a family member wanted to know only if the patient’s condition had improved or worsened. She stated *“There really is this thing where some people want to know everything and other people don’t want to know a thing at all”* (p. 27). Moreover, the most difficult part for the families is not knowing if the patient will succumb to his or her ailment, or live with no quality of life. It is important for

health-care providers to discern which family members want to know in detail the patient's prognosis or just what the status is that day. Most importantly, families want honest, and consistent information to be relayed to them empathetically and respectfully.

The results of this systematic review reveal that it is crucial for family members to be integrated into the plan of care for the patient, involved in decision making, and given honest, consistent, and timely information regarding the patient's condition. Feelings of helplessness, hopelessness, and fear often cripple the family members' ability to cope with their loved one's condition. The healthcare team can support the family by providing compassionate and empathetic care. The staff can provide individualized patient centered care by allowing the family to bring personal items of the patient that may encourage the patient to restore his or her health. Permitting the family to participate in caregiving allows them to regain some control, and reduces added pressure. Efforts should be attempted by the staff to reduce family waiting time outside the ICU, allow the family to stay at the bedside as long as possible, and to permit the family to participate in interdisciplinary rounds. The hospital should innovate a video describing the ICU experience that can be shown in the ICU waiting room. This will reduce the apprehension families feel when they see the ICU equipment and monitors. Visiting hours should be flexible to allow for family members who are traveling long distances or coming after work, to see their loved ones. The hospital should have appropriate waiting rooms and a place for the family to sleep if necessary. The coping mechanisms that the family utilizes to help them adapt to the crises should be encouraged (support from family members, praying, cultural traditions etc.). An additional finding to this study revealed that family members found comfort from other family members in the waiting room.^{19,29} Further research should be implemented to investigate this finding. Moreover, if health-care providers leave the needs of family members unmet, it may cause the family to disregard the treatment plan, distrust the health-care team, and may even result in a lawsuit. These feelings can be transferred to the patient.⁵⁴ Hence, it is of uttermost importance that healthcare providers foster healthy family relationships which in turn, reduces family stress, builds the foundation for trust in the healthcare team, and helps to improve patient outcomes.

Limitations

Although a systematic search was performed to identify all relevant studies, it is possible that some qualitative studies that addressed family experiences may have been missed. Contributing to the difficulty in finding studies is the use of the mesh term *qualitative* since only 1993. Additionally, due to resource limitations, studies published in languages other than English could not be included in this review. Although many of the studies did not give personal demographics of participating families, this review did capture the voice of families with family members in a wide variety of critical care specialty areas.

Conclusion

This systematic review had a high level of evidence based on the CONQUAL findings. The review has corroborated, clarified, and reinforced the knowledge about the family experience when a family member is critically ill and cared for in a designated critical care unit. The major

implications of this review are that family members experience feelings of isolation, helplessness and anxiety, and seek comfort in consistent, honest, and timely information.

Evidence Transfer

This systematic review revealed that family members of patients in the ICU may harbor feelings of isolation, helplessness, and anxiety and that timely, honest, and accurate information was used as an antidote. These findings were used to develop an infographic (See Appendix # IV) to educate the nurses on how to improve the ICU experience. According to Lamb et al.⁵⁵ an infographic is “a graphic representation of information that helps users visualize the "big picture" of an idea that might otherwise be difficult to understand” (p. 54).

The results of this review also offer recommendations to improve the quality of care provided to the family, including:

- Health-care providers (physicians, nurses) should keep the family informed on the status of the patient which helps to reduce anxiety
 - Avoid medical jargon
 - Information provided should be consistent, timely, and honest
- Physicians and nurses should effectively communicate with each other to avoid transferring misinformation to the family
- Allow the family members to stay at the bedside as long as possible
 - Avoid having them wait in the waiting room for long periods of time
 - Open visitation hours
 - Hospital should provide a place for the family to sleep in the event that they cannot stay at the bedside.
- Hospital should provide clean and welcoming waiting rooms
 - Promotes healing for the family
 - Reduces stress
- Integrate the family into the plan of care for the patient.
 - Allow the family to participate in multidisciplinary rounds.
 - Provide the family with options (if feasible) regarding treatment.
- Provide social/emotional support.
 - Confident, empathetic, and compassionate clinicians provide comfort for the family.
 - Encourage emotional support (etc. prayer, support from other family members or friends).
- Formulate an ICU orientation video that can be played in the ICU waiting room
- Allow family to bring in personal items of the patient (i.e. photographs, bible, etc.)
- Encourage coping mechanisms (i.e. family support, prayer, cultural traditions)
- Allow the family to partake in caretaking.

Conflicts of interest

There are no conflicts of interest in this systematic review.

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Appendix #II

Qualitative Data Extraction Instrument

JBI QARI Data Extraction Form for Interpretive & Critical Research

Reviewer Date

Author Year

Journal Record Number

Study Description

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete

Yes ☐

No ☐

Appendix # III

Table 3: Qualitative table of evidence

Author/Year	Methods for data collection and analysis	Phenomenon of Interest	Setting or Type of ICU/Country	Participant characteristics & sample size	Description of main results
Al-Mutair et al. 2014 ⁶	Semi-structured interviews of a sample of 12 family members	Identify the perceived needs of Saudi families of patients in the ICU	8 Medical-surgical ICUs in Saudi Arabia	A purposive sample of 12 family members (mean age of 25-44) of 12 patients in the ICU	The findings from this study reveal the importance of providing information to the designated family member, allowing the family to stay within close proximity to the patient, and allowing for flexible visiting hours. Incorporating these findings into practice, will help to improve their experience in the ICU setting as well as improve the delivery of care provided to both the family and the patient.
Agard and Harder, 2007 ³⁰	Qualitative in-depth interviews	Explore and describe the experiences of relatives of critically ill patients in the adult ICU	Adult neuro-surgical ICU in Denmark	A convenience sample of seven relatives (aged 39-72) of patients in ICU	Findings reveal that the family members felt that their questions were not answered to their satisfaction, and that their perception of the patient's

					condition was often different from the patient's actual clinical status. The results of the study recommend that ICU nurses should develop educational programs that address the complexity of the relatives' specific needs while in the ICU.
Blom, Gustavsson, and Sundler, 2013 ¹⁵	Phenomenological approach for reflective lifeworld research	Explore participation and support experienced by close relatives of patients in the ICU	8 bed hospital ICU in western Sweden	7 close relatives (between ages of 40 and 75) of patients in the ICU	Family members who participated in the care of the patient with support from health-care professionals helped to meet the needs of both the patient and the family.
Bond et al., 2003 ⁷	Exploratory qualitative descriptive design	Explore the needs of the relatives of patients with severe traumatic brain injury in the neuro-surgical ICU	11 bed neuro-ICU in a level 1 trauma center	Convenience sample of family members (ages from 41 to 61 years) of patients admitted to neuro-surgical ICU	The results of this study show that family members of patients in the neuro-ICU need to participate in the patient's care and be provided with consistent information to help alleviate their stress and improve their

					overall ICU experience.
Bournes and Mitchell, 2002 ³⁴	Parse's phenomenological-hermeneutic method was used to answer the research question: what is the structure of the lived experience of waiting?	To discover the experience of waiting and providing new knowledge about the experience of waiting from the family members of patients in an adult critical care unit	18 bed adult medical-surgical critical care unit in Canada	Participants were 12 people (10 women and 2 men >18 years old) who were family members or friends of patients in an adult critical care unit	The results of this study show that understanding the experiences of family members of patients in the critical care unit is essential in providing high quality health care.
Burr, 1998 ¹⁶	A multiple triangulation study of family members and ICU nurses using both qualitative (semi-structured interviews of family members) and quantitative (CCFNI) methods	Gain an understanding of the needs and experiences of family members and nurse family roles and relationships from the ICU nurses' perspective	General ICUs of 4 major teaching hospitals in Sydney, Australia	Participants consisted of one family member (> 16 years old) who was identified as the closest to the patient. However, different samples of family members were used for each method. Non-probability convenience sampling was used for both types of methodology	Family members often neglected their personal needs to meet the needs of the patient. The finding of this study reveal that family members needed support and re-assurance from health care providers as well as to express their feelings and concerns as a means of helping them to cope. Findings of this study demonstrate that ICU nurses can promote favorable patient outcomes by responding to the needs of family members of

					critically ill patients
Carlson et al., 2015 ³⁵	Longitudinal study, use of the Family Satisfaction with Critical Care questionnaire	Studied perceptions about ICU experiences and medical care in families of patients receiving ICU care for their injuries.	Level 1-trauma center, surgical ICU	29 spouses or first-degree relatives (average age 48 years old) of trauma patients admitted to a surgical ICU	Increased understanding of the effects of traumatic stress on family members may help improve communication and increase satisfaction of highly distressed family members
Chan and Twinn, 2007 ²²	Exploratory qualitative design using tape-recorded semi-structured interviews	Identify the major stressors affecting Chinese adults whose partner had been admitted to an ICU	ICU of a regional general hospital in Hong Kong	Purposive sample of 10 Chinese adults with a partner in an intensive care unit	Findings show the importance of uncertainty and the use of cultural beliefs and practices to bolster the development of coping strategies (i.e. seeking information and seeking support).
Coulter, 1989 ¹⁴	Qualitative research methodology was chosen using the Grounded Theory approach using informal in-depth interviews	Investigate the needs of family members of patients in intensive care units from the	6 bed adult intensive care unit in the north England	11 relatives of patients in the ICU in England	Family require full and accurate information about the patient's clinical condition, information regarding their progress, and to

		perspective of the family			have ready access to the medical as well as nursing staff. Results of this study show that having a nurse present at the interview between the medical staff and the family may give the relatives the psychological support needed and contribute to the establishment of a helping relationship.
Cypress, 2010 ³¹	Qualitative phenomenological methodology using 1-hour audiotaped interviews	Understand the experiences of patients, their family members, and the nurses in the ICU	ICU in a nonsectarian community hospital in the Bronx	Sample consisted of 5 nurses (between ages of 25 and 60 years old), 5 patients, and 5 family members (ages of 22 to 70 years old) in the ICU	Findings from this study show that participants felt that the provision of psychosocial support, physical care/comfort, and viewing the patient and their relatives, and the nurses as one unit or family help to reduce anxiety, builds family confidence in the healthcare system, and ultimately improves patient outcomes.
Eggenberger and Nelms, 2007 ²³	Family systems theory and existential	Understand and interpret the 'family	20-bed medical ICU of an 800-bed	11 families (total of 41 family	Family caring is enhanced with the presence of

	phenomenology using semi-structured interviews	experience' with an adult member hospitalized with a critical illness	of a mid-western tertiary-care University Hospital.	members from ages 13 to 79) of patients admitted to the ICU	nurses who recognize the importance of 'Being Family' for the family, acknowledge the significance of the nurse-family relationship and act on a commitment to be with and for the family.
Engstrom and Soderberg, 2004 ¹	Qualitative research interviews using the narrative approach	Describe partner's experiences when their spouses received care in an ICU	Hospital ICU in the northern part of Sweden	7 partners (one man and six women between 22 and 63 years old) of patients admitted to the ICU	Results of the study show how having family members and partners to be present at the bedside and being informed about the patient's medical condition helped them to cope and should be the basis of care provided.
Fontana, 2006 ²⁴	Descriptive phenomenology, using unstructured interviews	To describe the experience of a sudden life-threatening medical crisis from the prospective of the family	Large New England city with a level 1 trauma center	Small purposive sample of 6 participants of family members admitted to a level 1 trauma	Findings of this study show that not all family members want all of the information about the patient's medical condition all at once and health care providers should assess this need prior. Also, family members should have open

					access to visit the patient, and if information is provided, it should be clear and concise in terms that the family can fathom
Fridh et al., 2009 ⁴⁶	Phenomenological-hermeneutic method using audio-taped interviews	Explore close relatives' experiences of caring and the physical environment when a loved one dies in an intensive care unit (ICU)	3 ICUs in the Western part of Sweden	17 close relatives (> 18 years old) of 15 patients who died in three ICUs in the Western part of Sweden	A trusting relationship with the clinical staff is crucial for the close relatives' experiences and grieving process in the short-term. Returning for a follow-up-visit provided an opportunity for reconciliation and relief from guilt.
Frivold, Dale, and Slettebo, 2015 ²⁵	Phenomenological hermeneutical method	Illuminate the meaning of being taken care of by nurses and physicians for relatives in Norwegian ICUs	Regional or local level ICUs in southern Norway	13 relatives of critically ill patients treated in ICU	Family members in this study wanted to participate in the care of the patient, and heavily relied on information regarding the patient's medical condition and prognosis which offered support for them and understanding so that they can

					serve as a patient advocate.
Fry and Warren, 2007 ⁵	Phenomenological study with Heideggerian hermeneutic contextual analysis using tape-recorded interviews	Examine the perceived needs of the critical care family members in the waiting room viewed through their own words	Critical care unit	Purposive sampling of 15 family members of patients in the critical care waiting room. The participants gender consisted of 9 women and 6 men.	Families need to have trust in health-care professionals, be provided with information in terms they can understand regarding the patient's clinical status, and to be present at the patient's bedside. Results of this study show how integrating the relatives into the plan of care for the patient stimulates trust and promotes favorable patient outcomes.
Gaeni et al., 2015 ⁸	Qualitative content analysis approach	Explain the perspectives of families of ICU patients and nurses about informational support	ICU units of three teaching hospitals in Iran	Purposive sampling of 19 family members (> 18 years old) of 13 patients and 12 nurses (1 year of work experience in the ICU) who work in the ICU	Providing information and having the nurses readily available to answer questions about the patient's medical condition promotes their well-being as well as the well-being of the patient
Hansen, Rosenkranz, and Mularski, Leo, 2016 ⁴⁴	Qualitative content analysis using open-ended question	Understand family members' perspectives regarding overall care of	2 adult ICUs at 2 healthcare institutions in the U.S.	106 Family members (ages 22-88) of medical patients who remained 48	Interventions from health-care providers to improve the experiences and reduce anxiety

		medical patients receiving intensive care	Pacific Northwest	hours or more in 2 adult ICUs	and stress of family members in the ICU include improving communication between family members and the health care team, integrating them into decision-making, supporting their comfort needs, and maintaining patient privacy and appearance.
Hekmatpou and Ebrahimi-Fakhar, 2015 ³	Qualitative design and a content analysis approach using semi-structured interviews	Explore the perceived needs of the families of hospitalized patients in critical care units	CCU in one of the several teaching hospitals in Arak, Iran	Purposeful sampling of 16 participants (5 spouses, 4 children, 5 mothers, 1 brother, and 1 sister) of patients in the CCU	Health-care professionals can improve the family's ICU experience by providing them with accurate information which eases anxiety as well as provide sufficient rooms for them to sleep to bolster healing.
Henrich et al., 2011 ¹⁷	Mixed-method study using the Family Satisfaction Survey (FS-ICU)	To describe the qualitative findings from a family satisfaction survey to identify and describe the themes that characterize family members' intensive care	23 ICUs in Canada	Family members of patients in 23 ICUs from across Canada. Total of 1381 surveys were distributed and 880 responses were received	Improving the quality of care provided to the patients, demonstrating compassion and respect to the family and patients, and improving the communication between family and health care

		unit experiences			providers can better meet the physical and emotional needs of the families and improve their ICU experience
Hetland et al., 2018 ³²	Quantitative content analysis of text using an electronic mixed-method survey	Describe critical care nurses' approaches to involving family caregivers in direct patient care	Mixed-method survey	Convenience sample of 374 critical care nurses in the U.S. who were subscribers to one of the American Association of Critical Care Nurses social media sites or electronic newsletters	Active family involvement in routine care of ICU patients can reduce anxiety, increase family satisfaction, and contribute to feelings of family connection with their critically ill family member.
Hoye and Severinsson, 2010 ²⁷	Gadamerian hermeneutic design, data collected via in-depth interviews	Illuminate the experiences of multicultural family members in ICUs in hospitals when a loved one was critically ill	3 university hospitals and one regional hospital in Norway	5 family members (first generation immigrants) of patients in the ICU	Nurses need to be sensitive to the families' cultural customs in order to meet their expectations in a respectful way. Strategies for improving nurses' competence can include in-service training.
Hughes, Bryan, and Robbins, 2005 ²⁶	Qualitative methods with techniques from the grounded theory using tape-	Investigates relatives' overall experiences of the critical	2 CCUs in southeast England	A convenience sample of 8 relatives (aged 18-65) were recruited from	Results of this study show that relatives may receive more information

	recorded semi-structured interviews.	care environment and how staff perceived these experiences		2 CCUs in England and 5 staff nurses (aged 18-65) were recruited from 1 CCU in England	regarding the patient's condition than they are ready for. This research study suggests episodic information should be provided to the patient as it will help reduce their anxiety and stress.
Hupcey and Penrod, 2000 ⁴⁷	Qualitative study using the grounded-theory method	Investigated the changes in responsibilities and the impact these additional responsibilities (financial decision making and child care) had on spouses of critically ill patients	Rural tertiary-care medical center	Theoretic sampling of 12 spouses (aged 26 to early 60's) of critically ill patients	Families should be made aware that by turning some of their financial and personal responsibilities over to others, they would be better able to support the patient and may be more willing to accept the help
Hupcey, 1999 ⁴³	Techniques of grounded theory with the use of in-depth unstructured interviews	Examine how families and nurses interact to increase or decrease the family's involvement in the ICU, how nurses maintain control, and how families remain on guard	Hospital ICU	Theoretical sampling of 11 relatives of patients in the ICU, 10 ICU nurses, and 30 ICU patients	Nurses in this study maintain control by limiting visiting hours, not allowing family to participate in patient care (viewed as family impeding on their care for the patient), and asked the family to step out of the room when care

					<p>is rendered for long periods of time. Families felt they needed to be comforted by the nursing staff, and often remained on guard in fear of interfering with patient care. Nurses need to understand how their actions can help or hinder the family's ability to adequately support their critically ill loved one.</p>
Jamerson et al., 1996 ²	Retrospective, descriptive, and qualitative with the use of focus groups and individual unstructured interviews	Describe the experiences of families with a relative in the ICU	Surgical-trauma ICU in a midwestern university-affiliated tertiary medical center	18 women and 2 men (>18 years old) with relatives in the surgical trauma ICU	Family members experienced a sense of uncertainty and fear of not knowing what will happen to the patient. Results of this study show if information about the patient's condition was given and the family receive the needed support from the staff, then those feelings of uncertainty was

					resolved. Family needs should be anticipated and addressed.
Johansson, Fridlund, and Hildingh, 2005 ⁴⁵	Descriptive research design with a qualitative approach	Generate a theoretical understanding of what relatives experience as supportive when faced with the situation of having an adult next-of-kin admitted to critical care	Adult ICU patients in southwest Sweden	Theoretical sampling of 29 adult relatives of adult ICU patients in Sweden	Healthcare professionals need to understand how important it is for them to have control of their vulnerable situation, and that when they encounter professionalism, it gives them a sense of empowerment
Koukouli et al., 2018 ¹⁸	Descriptive qualitative research design using an inductive thematic content analysis approach, semi-structured interviews	Explore the experiences, needs, and coping strategies of families of patients admitted to the adult intensive care units	Adult Intensive Care Unit of three hospitals on the island of Crete, Greece	Non-random purposeful sampling of 14 family members of adult patients hospitalized in the ICU	Meeting family's need to be near the patient and be reassured that he/she is being cared for with dignity and respect by applying flexible visiting hours. Effective communication should be promoted as this is a source of empowerment, reassurance, and hope for the family members.
Kutash and Northrop, 2007 ¹⁹	Qualitative design using semi-structured interviews	Explore family members' perspectives and experiences of waiting rooms	18 bed neuro-science ICU	A convenience sample of 6 visitors in the waiting area of the neuro-ICU	Intensive care waiting rooms that are comfortable and in close proximity to

		in adult intensive care units			patients can ease the difficulties of waiting as well as serve as emotional support for family members.
Lam and Beaulieu, 2004 ⁹	Descriptive, exploratory, multiple-case design methodology using semi-structured interviews	Explores the experiences of family members of patients with an emergent admission into a neurological intensive care unit	Neurological ICU in a large metropolitan university	Convenience sample of 13 family members (>18 years old) of 10 patients in the neuro-ICU	Findings suggest families seek information when they are ready, find knowledge reassuring, and they feel reassured when they can participate in patient care. Interventions from health-care workers to ensure family comfort and coping should be geared towards assessing the families' willingness to learn, and integrating them into the plan of care for the patient.
McKiernan and McCarthy, 2010 ²⁸	Phenomenological Heideggerian hermeneutic method using in-depth interviews	Describe the lived experience of family members of patients in the ICU	Medical-surgical ICU	A purposive sample of six family members (> 18 years of age) of adult patients in the ICU	Families need to be accurately informed of patient's medical condition, to be present at the bedside, and to also receive care and support from

					healthcare providers to help cope with the patient's illness and improve their overall experience.
Nelms and Eggenberger, 2010 ¹⁰	Family systems theory and existential phenomenology using semi-structured interviews	Explicate the essence of family critical illness experience and the family vision for the kind of care families required and desired from nurses and their implications for family nursing practice	ICU of a large Midwestern Hospital	11 families (41 individual family members) with a critically ill loved one in the intensive care unit (ICU) of a large Midwestern hospital	Nurse-family meetings acknowledge suffering and vulnerability of families when a loved one is critically ill and afford families an opportunity for honest sensitive communication with nurses.
Plakas, Cant, and Taket (2009) ¹¹	Social constructionist version of grounded theory using in-depth interviews	To explore the experiences of critical care patients' families in Greece	ICUs of 3 general district hospitals in Athens, Greece	25 relatives (19 females and 6 males) of critically ill patients in the ICU	Families often felt a disconnect in communication with the patient due to their medical condition which caused

					sorrow, felt they needed to be close to the patient to ease anxiety, and relied on religion for emotional support. Health care providers can provide the support families need to help them cope with the patients' condition once their experiences and feelings are fully understood.
Plowfield, 1999 ⁴⁸	Phenomenological design using in-depth interviews	Examine the lived experience of families who wait following a sudden unexpected neurological ICU hospitalization	Neurological intensive care unit	Sample of 12 families (ages 22-68 years old) of patients (ages 16-68 years old) who suffered a sudden neurological condition	Interventions that are proactive in providing timely information and assisting families in their search for meaning will be beneficial to both the nurse and family. Nurses may find that empowering families of the critically ill leads to improved patient and family outcomes following crisis

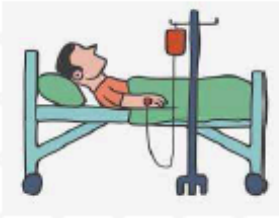
Rupert, 1993 ²⁹	Qualitative phenomenological design using semi-structured interviews	Describe the lived experiences of wives whose husbands were hospitalized in critical care units	General surgical ICU located in the medical center of a large metropolitan city in southwestern U.S.	Convenience sample of 8 wives whose husbands were admitted to the ICU	Results show spouses need consistent and accurate information from all health-care providers, allowed frequent visitation, to help promote the development of coping strategies as well as a trusting relationship with health-care providers
Soderstrom, Saveman, and Benzein, 2006 ²¹	Descriptive and interpretive design including observations and interviews	Describe and interpret interactions between family members and staff in intensive care units	Hospital ICU at a university hospital in the south of Sweden	24 family members (ages of 14 to 73 years old) of 10 ICU patients	The provision of unambiguous information to the family is critical because it fosters positive family interactions for the development of mutual understanding and helps the family to adjust

					well to the hospital system
Soderstrom et al., 2009 ⁴⁹	Qualitative design using a hermeneutical analysis via tape-recorded interviews	Describe and interpret the family adaptation during the ICU hospitalization and up to 18 months after discharge	Hospital ICU	Individual and family interviews with 8 families including 31 family members	Family members can adapt to the patient's condition by being able to stay close to the patient and receiving accurate information about the patient's medical condition from the staff. Supporting an open conversation within the family is essential for adaptation.
Urizzi and Corrêa, 2007 ³⁶	Qualitative study using phenomenology as the methodological framework via tape recorded interviews and transcription	Aim is to understand the experience of family members of patients in the ICU	The Santa Casa Hospital in the city of Londrina-PR, Brazil	17 family members of patients in the ICU	Results of the study show that family members were fearful that their loved one would die, were empathetic regarding the patient's condition, and expressed their fear of the ICU setting. Health care providers should incorporate family members into the plan of care for patients which helps ease

					their anxiety and fear.
Verhaeghe et al., 2007 ¹²	Qualitative approach using the grounded theory with the use of in-depth interviews	To assess the interplay between hope and the information provided by health care professionals	2 Belgian hospital ICUs; a university hospital and a large regional hospital	Sample of 22 family members of 16 patients with traumatic coma. Nine of the patients were men, seven women ages between 17-85	There is relationship between hope and concrete information. The process of hope is crucial in coping with traumatic coma and information can facilitate this process.
Verhaeghe et al., 2010 ⁵⁰	Qualitative approach using the grounded theory via in-depth interviews	To identify and describe the basic psychological process linked with the focus of family members' functioning during the acute phase of traumatic coma	2 Belgian hospital ICUs; a teaching hospital and a large general hospital	Sample of 22 family members of 16 patients (between ages of 17-85 years old) with traumatic coma	Families go through the first phase of acute coma which entails the need to protect the patient's life which in-turn may cause them to neglect themselves. Nurses and physicians need to take the initiative to provide information and reassurance that the patient is in good hands and no further care can be given than what was already provided

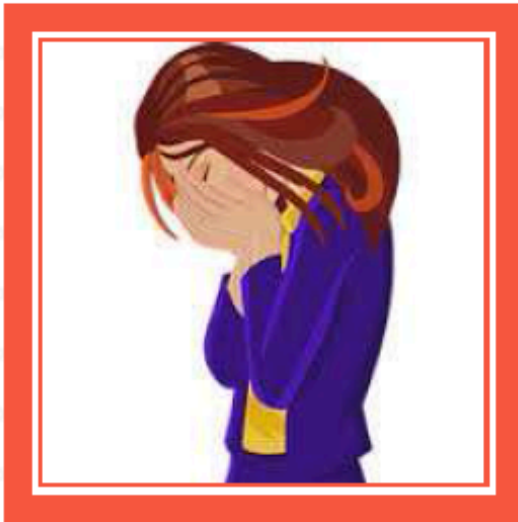
Verhaeghe et al., 2010 ³⁷	Qualitative approach using the grounded theory via in-depth interviews	To identify and describe the basic psychological process linked with the focus of family members' functioning during the acute phase of traumatic coma	2 Belgian hospital ICUs; a teaching hospital and a large general hospital	Sample of 22 family members of 16 patients (between ages of 17-85 years old) with traumatic coma	It is essential that health care professionals to realize that family members will only leave the hospital if they are sure the patient is in good hands. Establishing a trusting relationship with the family, allowing for flexible visiting hours, and being empathetic helps to improve family care.
Walters, 1995 ⁵¹	Hermeneutic study using tape recorded interviews	Describes the lived experiences of relatives of critically ill patients who were cared for in an intensive care unit of a large tertiary hospital in metropolitan Sydney, Australia	Tertiary hospital in metropolitan Sydney, Australia	15 randomly chosen female family members of critically ill patients	The results of this study provide critical care nurses with the opportunity to attune themselves to the lived experience of the families of critically ill patients. Being able to understand people's experience can lead to nursing care that is responsive to the complex experiences of the intensive care unit

Wilkinson, 1995 ²⁰	Thematic content analysis using tape-recorded interviews	To establish the self-perceived needs of family members of patients in a general ICU	8 bed general ICU in Essex, UK	Purposive sampling of 6 relatives of patients admitted to a general ICU	Relatives have the need for more information, be in close proximity to the patient, social support, and a caring environment. Early family assessment may assist in highlighting areas of need and will facilitate the development of a family care plan.
Wong et al., 2015 ¹³	Qualitative enquiry with the adoption of the grounded theory with the use of in-depth interviews. Data analyzed using thematic analysis	Examine the families' experiences of their interactions with physicians and nurses in the ICU	Mixed ICU (Trauma and cardiothoracic surgery) in a large metropolitan hospital in Australia	Theoretical sampling of 12 family members (>18 years old) of 11 patients admitted to the ICU	Families provide the patients with psychosocial support and thus, if the families need of being provided with consistent and honest information, they are at risk for emotional distress which compromises the support they can give the patient. Patient and family-centered care should be considered in the delivery of health care



A GUIDE TO IMPROVING THE FAMILY EXPERIENCE IN THE ICU

Family members often experience feelings of anxiety, fear, and uncertainty when their loved one is admitted to the ICU. Healthcare is focused on providing patient-centered care and oftentimes, the needs of the family are overlooked. This guide was formulated to help health-care providers improve the family experience in the ICU.



Provide emotional support:

- o Confident clinicians help to ease anxiety.
- o Encourage means to provide emotional support (etc. prayer, meditation, attending church)
- o Offer pastoral care if available.

Allow the family members to stay at the bedside as long as possible which fosters healing for the family:

- o Open visitation hours
- o Allow the family member to stay overnight at the bedside.
- o Hospital should provide a place for the family to sleep in the event that they cannot sleep at the bedside.





Health-care providers (doctors, nurses) should keep the family informed on the status of the patient which helps to reduce anxiety:

- o Avoid medical jargon
- o Health-care providers should provide consistent information regarding the patient's prognosis to avoid confusion.
- o Update the family promptly if there is a change in the patient's condition.

Integrate the family into the plan of care for the patient.

- o Allow the family to participate in multidisciplinary rounds.
- o Provide the family with options (if feasible) regarding treatment.
- o Allow the family to participate in care-giving if possible (etc. feeding, brushing teeth, bathing).



Provide social support:

- o Encourage the family to bring personal items of the patient.
- o Encourage support from family or friends.
- o Encourage the continuity of cultural traditions

Addressing the needs of the family allows the family to heal, reduces stress, and feelings of hopelessness. Consequentially, the family will be able to offer emotional and social support to their loved ones.