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Serpil Topçu

Koç University, stopcu@ku.edu.tr

Şule Ecevit Alpar

2- Marmara University Institute of Health Sciences, salpar@marmara.edu.tr

Bilgi Gülseven

2- Marmara University Institute of Health Sciences, bgulseven@marmara.edu.tr

Ayda Kebapçı

Koç University School of Nursing, akebacpi@ku.edu.tr

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Patient experiences in intensive care units: a systematic review

Serpil Topçu, *Koç University School of Nursing, Istanbul, Turkey, stopcu@ku.edu.tr*

Şule Ecevit Alpar, *Marmara University Institute of Health Sciences Istanbul, Turkey, salpar@marmara.edu.tr*

Bilgi Gülseven, *Marmara University Institute of Health Sciences Istanbul, Turkey, bgulseven@marmara.edu.tr*

Ayda Kebapçı, *Koç University School of Nursing, Istanbul, Turkey, akkepaci@ku.edu.tr*

Abstract

The aim of this systematic review is to analyze the data gathered from studies conducted to determine patient experiences in intensive care and levels of the recollection of the intensive care period that were published between December, 1998 – April, 2013. The systematic review was carried out screening of the related publications. The findings of the systematic review were studied under the following two titles: “remembering the intensive care period” and “recalled experiences” of patients. Studying 15 papers which were found suitable to the inclusion criteria of the review indicated that majority of the patients had recollection of the intensive care process. The physical experiences of the patients were pain, sleep disturbances, discomfort, inactivity or over-activity, noise, thirst, headache, discomfort due to the endotracheal tube (ET), technological support, medical activities, and difficulties in aspiration and swallowing. On the other side, psychological experiences were hallucination, nightmares, fear, worry, anxiety, depression, loneliness, and thoughts about death, panic, nervousness, uncertainty, and despair. In addition, it was seen that patients experienced some communication difficulties. As a result of the systematic review, it was seen that patients could remember the intensive care period, and the number of negative experiences in intensive care were more than the positive ones.

Keywords

Intensive care, intensive care unit, memory, patient experiences

Introduction

Intensive care units (ICU) are where patients whose survivor functions are impaired and who need further technology, intense medication, close follow-up, and care to be able to continue their normal functions are located.¹ Thanks to the improvements in technology, the increase in the number of qualified research, and guidebooks that are frequently renewed, necessities on physical care have been met successfully and rates of survival have increased.^{2,3} A positive intensive care process could enable the physical and psychological well-being of patients after the discharge, and thus would prevent a negative change in the quality of their lives. Therefore, patient care necessitates a health team with special training, which has full knowledge of the practices related to intensive care, follows and adopts research findings based on evidence, and would exercise the precautions regarding the complications that may occur after discharge due to the intensive care period. The teams working at intensive care units, where keeping patients alive is of top priority, sometimes may ignore the fact that patients have psychological needs and focus mainly on fulfilling physiological needs. Precision towards psychological needs would increase with the guidance of studies^{4,5} which show that psychological support during the recovery period contributes positively to patients.

Many studies show that patients negatively evaluate their intensive care period due to experiencing many physical problems such as pain, discomfort, and sleeplessness in the intensive care unit.⁵⁻⁷ Additionally, patients with the support of many equipment and healthcare professionals that are not familiar and stranger for them, called as simply “patient.” This affects both the psychological and the physical well-being of patients.^{5,7,8} An increasing number of studies show that there were a relation between post-traumatic stress disorder and patients’ negative experiences in intensive care.^{9,10} Patients’ experiences regarding intensive care are also the quality indicators of an ICU.⁵ A better understanding of patients’ experiences could help health professionals create better intensive care experiences and outcomes for patients.

This systematic review was conducted with the purpose of reaching scientific consensus through the findings of papers that analyzed the experiences of intensive care patients and the levels of recollection of the intensive care period.

Method

The purpose of this study was to systematically review studies that examine patient experiences and recollection

of the intensive care period. Literature review for the studies conducted between March, 23 – April, 24, 2013.

The steps for the systematic review are as follows:

Determining the proper questions for the analysis

Patients in intensive care units are primarily monitored for their physiologic changes by a health care team. Communicating with the patient is of secondary importance and mostly forgotten. It is thought that patients are not aware of what is going on around them and they will not remember the process that they experience.¹² This systematic review planned to define the experiences of patients in intensive care units. Questions generated in this context were 1) “Do patients remember their ICU experiences?” and 2) “How do patients define their ICU experiences?”

Literature review

Literature review was carried out in three steps: a) electronic databases, b) manual research in relevant journals, c) references of the papers used. The databases where papers were screened and the number of studies reached is given in Table 1. Keywords used during the electronic database search were “yoğun bakım”, “yoğun bakımdaki hasta deneyimleri”, “intensive care”, “memory”, “patient experiences.”

Determining the inclusion criteria for the systematic review

The studies with the following features were included in the systematic review: the papers a) which were published between 1998 and 2013, b) which were published in English or Turkish, c) whose sample group consisted of patients that were 18 years old and above, d) whose sample group consisted of patients who were conscious and could be communicated with after the intensive care, e) whose sample group consisted of patients who were transferred or discharged from the intensive care, f) whose

sample group consisted of patients who stayed in intensive care for at least a day, g) whose sample group consisted of patients whose extensive care experience was maximum 6 months prior to the relevant study.

Compounding the studies reached

A total of 1390 papers were reached with the keywords and 15 papers that matched specified criteria were included into the research. The process of choosing and eliminating the papers that matched the inclusion criteria is shown in Figure 1.

Analyzing and Locating the Findings

The findings of the 15 studies that were selected for the systematic review were analyzed and discussed in this paper.

Ethical Considerations

All of the papers that were published in journals and were reached through open databases.

Results

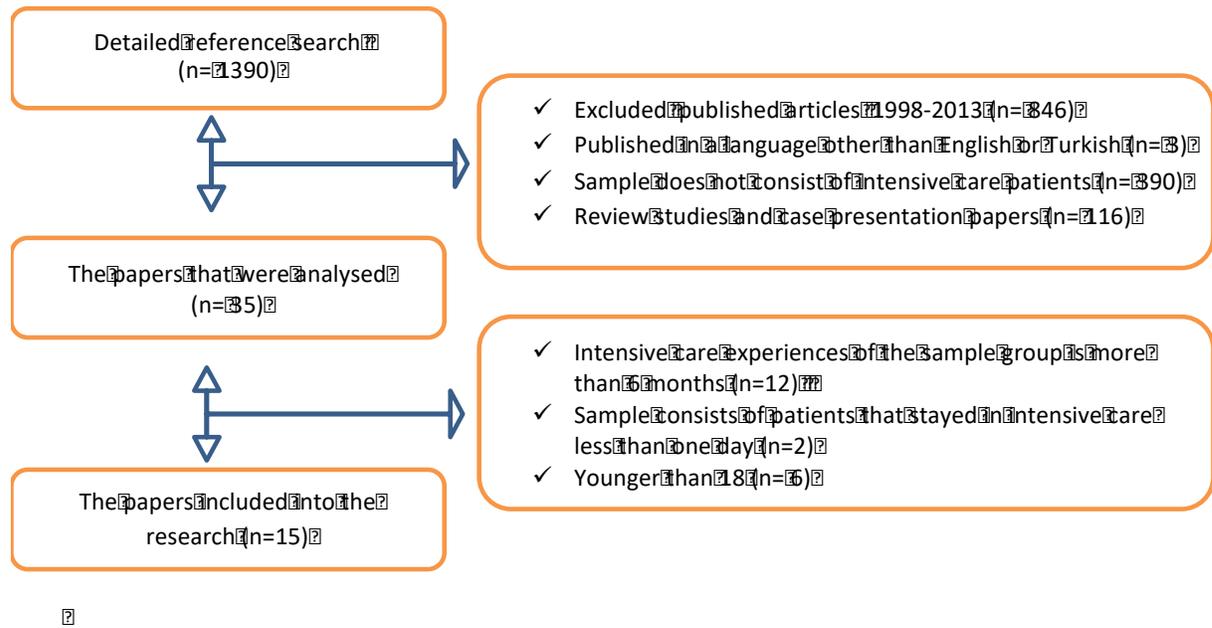
Samples of the 15 studies that were included into the systematical review included between 4 – 464 patients and consisted of individuals that were at least 18 years old. Duration of stay in the intensive care unit ranged between 36 hours and 133 days. In all selected papers, data were collected after the patients were transferred out of the intensive care unit. Face-to-face interviews and data collection by phone/email methods were used for data collection by the studies that were designed as descriptive, prospective, qualitative, and/or quantitative. The findings were discussed under two titles (Table 2 at end of article):

Remembering the Intensive Care Period

As a result of the systematic analyze, it was found that the duration and feature of sedation was not clearly referred in

Table 1: Databases and the number of studies reached

| Database | Number of Studies |
|--|--------------------------|
| Medline | 33 |
| EBSCO | 276 |
| CINAHL | 5 |
| Google Scholar | 242 |
| Ovid SP | 770 |
| Intensive and Critical Care Nursing | 12 |
| Nursing in Critical Care | 18 |
| Searching by hand from relevant journals | 14 |
| References of the papers acquired | 20 |
| Total | 1390 |

Figure 1. The process of choosing and eliminating the papers

some papers, while in some others sedation was not mentioned at all.^{4,6,13-17} Leur et al., whose sample consisted of patients that were sedated while they were already intubated, indicated that a total of 125 patients recalled their intensive care process, although they were sedated.¹⁸ Similarly, the other three studies showed that patients recall intensive care days despite being sedated.^{7,19,20} Other studies in which duration of sedation was not addressed found that patients mostly recall the intensive care process as well as the physical and psychological discomfort.^{4,6,14,16,17} Özdemir concluded that patients who had pain recall their intensive care experiences more than the others.²¹ Out of the fifteen studies that were included in the review, only the patients in Adamson et al.¹⁵ stated that they could barely remember the process but could describe some moments that they had been through. Some patient expressions about recollection were specified in the qualitative studies are as follows:

“It was not nice to be in intensive care, but I cannot remember much.”¹⁵

“Intensive care was like a factory. Everybody was busy taking care of the patients. They were running here and there. So intense, I am used to beats and crashing noises in the factory. It disturbed me so much to watch patients.”²⁴

“I remember thinking that I would never go home again.”⁸

“It was a quite distressing atmosphere. It looked like a battle field. I remember a patient making animal noises.”⁴

Patient Experiences in an Intensive Care Unit

Intensive care experiences of patients were discussed under two titles: physical and psychological experiences. It was found that patients describe both positive and/or negative experiences, according to the studies that were included in the systematic review (Table 2).

Physical Experiences

The physical experiences described by the patients as negative were mostly pain, sleeplessness, discomfort, inactivity or over-activity, noise, thirst, headache, discomfort due to ET, technological support, medical activities, aspiration and swallowing difficulty.^{4,8,13,14-18,20-22,23} Patients usually remembered the intubation period as a negative experience. Similarly, equipment like the oxygen mask, saturation prop, and nasogastric tubes caused loss of comfort.^{6,18,20,22} Patients expressed their physical experiences as following:

*“Being tied to the machine. Alarms, continuous rush. Pushing, poking, pain, seeing a lot of ill people around is frightening. All the IV fluids, dripping serum. Doctors all the time. A peculiar smell.”*²⁴

*“I will never forget the pain that I went through. I could never ask the doctors or nurses what was happening to me. This is just one of the many things I experienced there.”*¹⁵

*“It was impossible to sleep because of the noise.”*²²

*“It was extremely cold; I was cold all the time I remained in intensive care.”*⁸

*"I was very thirsty and they gave me some water by syringe. I panic each time I remember that thirst."*¹⁸

Psychological Experiences

Patients have both positive and negative psychological experiences related to the intensive care period. Experiences are associated with the individual perception of the patient and/or the manner and behavior of the health team. The majority of the patients noted communication blocks and difficulties such as having difficulty in speaking and communication due to the ET.^{6,7,13,14,18} Other experiences of the patients were hallucination, nightmare, fear, worry, anxiety, depression, loneliness, thoughts of death, panic, nervousness, uncertainty, and despair^{4,7,13-16,20}. Patients expressed their psychological experiences as follows:

*"I thought I could not go home because I had lost my wallet and passport."*¹⁸

*"The need to communicate is not only verbal; non-verbal communication can be set up in many ways. The person is right by you, with you, knows what you want, and gives you what you want, in non-verbal communication."*¹³

*"I felt that I had changed... I could not figure out what was imagination and what was reality. I had never had such a dilemma before. It was a really strange feeling."*¹³

*"My doctor told me I looked fine, but I was not feeling well."*¹⁴

*"I was in another world. I saw faces and talked to them. There were some strange things. I believed all those were real."*¹⁵

*"I was embarrassed to lie naked in bed."*¹⁸

According to Granberg et al.,²² patients evaluated the nurses who did not communicate much with them and practiced the procedures without any explanations as "bad", while they evaluated the nurses who took continuous care of them, talked to them, and treated them kindly as "good." Another study found that some verbal and non-verbal communication techniques help patients to feel better and ease the pain.¹³ Özdemir noted that patients with pain have more positive intensive care experiences compared with the patients with no pain.²¹ Studies showed that patients feel better and intensive care experiences become positive with the caring attitude of the healthcare staff.^{7,13,15,16} Positive behavior raise the trust towards healthcare staff.⁶

Negative experiences of the patients were: lack of respect,^{4,7} an unfriendly, tense atmosphere,⁶ and lack of communication.⁴

Patients expressed their experiences related to the health personnel as the following:

*"A nurse has lots of work to take care of in a service. However, while in intensive care, we want one of the nurses to be there for us whenever we need them."*¹³

*"There were angels (the nurses) there. They did everything for me, they treated me as if I was a baby, a princess. They took very good care of me, but I still want to go back home."*²²

*"The nurse was tired of my requests."*¹⁸

*"I remember them say, the blood pressure is falling down 60, 57, 55... Another voice said, let me know when it falls down to 50, that's when we can kill them all/cut it. I still think of this from time to time."*¹⁴

The psychological demands that patients experience during ICU are to see and come together with their family. Wang et al. stated that family support and visits are effective during the recovery period.¹⁶ Patients reported that they missed their spouses and friends,¹⁴ scared of losing their loved ones²³ and worried about their family during hospitalization in the ICU.⁶

Discussion

This review evaluates the intensive care experiences of patients and their recollection of these experiences, through the findings acquired from fifteen studies. Defining patient experiences will provide a guide for all health care personnel to help them plan their approach and care of patients. Although the studies were conducted with different sample sizes and types and many common points were determined on patient experiences. The argument was structured under two titles which was supported by other findings from the literature.

Remembering the Intensive Care Period

There is no sample group that includes patients who recollect whole period of the intensive care. The patients reported either complete or partial recollection. Recollection requires to be conscious and awake during the incident. The incidence of delirium in intensive care, which can affect recollection and correct recollection, is between 40 – 80%.²³ The cohort study by Roberts et al. determined a decrease in the skills to perceive and interpret reality of the patients in delirium, compared to the patients who were not.²⁴ The same study noted that recollection levels of the majority of the patients were realistic. Other factors that block patients to recall memories are sedation, medical treatments, the severity of illness, and data collection time.¹⁴ Seven studies discussed in this systematic review which evaluated the intensive care period recollection of patients found high recollection rates,^{4,7,14,17,19} whereas three studies found that most patients had no recollection or did not have clear recollection.^{14,15,20} Sedating patients

in intensive care in order to put them to sleep is used to suppress the stress response in critically ill patients, decrease anxiety, increase the tolerance for ventilator support, facilitate nurse/doctor interventions such as aspiration, invasive attempts, and dressings, and to improve patient comfort.²⁵ Recollection of the intensive care can be harder for patients who were sedated. The study by Capuzzo et al., found that sedation negatively affects recollection.²⁰ However, one third of the patients of the same study reported clear recollection of the intensive care period, despite sedation. Therefore, nurses, who spend the longest time with patients in the clinic need to use their communication skills at the highest level and also make the other health care personnel use their communication skills.

Patient Experiences in an Intensive Care Unit

Turkish and English studies included in this review show no differences in terms of patient experiences. The common experiences singled out in all studies were grouped under the titles “discomfort” and “difficulty in communication”. The reasons of discomfort were mainly the endotracheal tube, medical responses, noise, hallucination, and pain. There are studies showing that Endotracheal Tube leads to discomfort in ICU patients.^{6,13,16,18,20,26} The discomforts recalled by patients were not being able to speak because of the ET¹³ and discomfort due to the ET^{18,20} and the aspiration process.^{6,16} It is impossible to make a patient feel completely comfortable without ending the intubation; however, a partial comfort can be provided during the unavoidable intubation process by the responses of nurses. The level of discomfort caused by the ET can be decreased by methods such as using non-verbal communication techniques, closely monitoring patient-mechanical ventilator compliance, evaluating the respiratory rate, pulse and blood pressure, regularly checking the location and fixation of the intubation tube, frequently cleaning the oral secretions, and by explaining all procedures to the patient.²⁷

Pain is a cause of discomfort which is seen frequently in ICU and whose severity varies from person to person. Many studies show that patients in intensive care experience pain due to various reasons.²⁸⁻³² Pain-related experiences of patients result from variety of reasons such as drain tube, endotracheal tube, inserting and removing the catheter, trauma, immobility for long time, routine nursing care, aspiration, surgical attempts, changing the dressing, and existing diseases.³³ Özdemir stated that patients with pain have more positive experiences of the intensive care period.²¹ Although this result seems to be conflictive, the fact that patients who had pain got more attention and their pain was tried to be eliminated might cause to this result. What nurses can do to prevent the pain are evaluating the location and severity of the pain as well as the factors that increase/decrease the pain, making

explanations to the patient before any intervention, trying to eliminate the causes of the pain, helping the patient to have the proper position to be comfortable, and before the painful invasive attempts administering analgesic drug.²⁷ Hunt noted that a majority of the patients reported that they recollect the pain relief as a result of the attempt made by nurses.¹³

It was seen that difficulty in communicating, fear due to uncertainty, hallucinations, nightmares, anxiety, and intensive care responses lead to psychological discomfort in patients. Granberg et al. stated that patients evaluated the nurses who made explanations and talked to them, and took care of them as “good”, while they evaluated the nurses who applied the procedures without making explanations as “bad.”²² Hunt noted that patients were focused on the presence of nurses and reported feeling better when they took care for them.¹³ Similarly, Wang et al. denoted that patients reported feeling safe with the positive attitudes of the health personnel.¹⁶ Patients’ comfort can be increased by simple nursing responses like checking into the factors that increase and decrease anxiety, encouraging the family/relatives to pay more frequent visits, informing patients, using nonverbal communication in order to enhance communication, and teaching alternative communication techniques to the patients. According to Russell et al., patients reported anxiety due to noise.⁴ Avoiding patients from seeing other patients going through an immediate treatment or die, making explanations about the noise around, orienting the patients about the environment they are in can be counted among the interventions that are effective in decreasing the fear. Wang et al. stated that patients reported the positive effect of the family’s visits and support for their recovery.¹⁶

Sleep disturbances withdrawal is another problem faced by patients.^{5,7,14,18} Tunçay et al. found that 60% of the intensive care patients had sleeping problems.³⁴ The common reasons were continuous illumination inside ICUs, not being able to differentiate between day and night, being subject to diagnosis, treatment, and care with frequent intervals, and interruption of sleep due to pain and noise. The problems related with sleeping can be solved by planning nursing interventions in a way that would not disrupt patients’ sleep, performing as few procedures as possible during night time, reducing the noise sources –staff voices, alarms, telephones, etc. – minimizing sounds, switching off the lights by bedsides after a certain hour at night, controlling the ambient temperature, helping the patient relax, feel better, and have a suitable position that facilitates sleeping, and the most important of all, trying to relieve pain or stressful situations. Nightmares during sleep in intensive care are among bad experiences reported by patients.^{6,7,14,20,23} Nightmares are associated with lying under lights all the day, sedation, being at an unfamiliar place, not being able

to see the loved ones, and post-traumatic stress disorder.³⁵ Although it is not possible to prevent nightmares completely, their frequency can be reduced by eliminating the reasons that cause discomfort.

Limitations

The review contains several limitations. The first limitation is the difficulty in generalizability of the results due to methodological differences (type of the study, question forms, number of samples). Secondly, the explanations regarding the sedation of patients and status of the patients connected to mechanical ventilator were not specified in some of the studies that were included into the review. Additionally, some of studies didn't provide any information on the recall the intensive care period. Thus, there may be some selection bias or insufficient report of null findings.

Conclusion

This study underlined the positive and negative experiences of the intensive care patients and, in light of the findings, tried to draw attention to reinforce the positive attitudes of the health personnel and to change negative attitudes. Negative experiences of patients can be mostly turned into positive, with proper nursing attempts. Finding solutions to the physical and psychological problems of intensive care patients, using empathetic approach technique which is very well known by nurses during the resolution process, and through their roles as an instructor and a researcher, guiding the health personnel to provide comfort for patients are not difficult goals to achieve in the nursing profession which adopts an integrative approach.

Since sociological and cultural history are important in interpreting experiences, it is necessary to conduct detailed research in every country in the future, in terms of patient experiences in intensive care in order to eliminate the interpretations associated with these differences, so that the situation in different countries and patient can be identified.

References

1. Vincent JL, Singer M, Marini JJ, et al. Thirty years of critical care medicine. *Crit Care*. 2010; 14:311.
2. Çelikel T. Dünyada ve Türkiye'de Yoğun Bakım Uzmanlığı. *Türk Yoğun Bakım Dern Derg*. 2001; 1(1):5-9.
3. Russell S. An exploratory study of patients' perceptions, memories an experiences of an intensive care unit. *J Adv Nurs*. 1999; 29 (4): 783-791.
4. Hofhuisa JGM, Spronka PE, Stel HF, Schrijvers AJP, Rommesa JH, Bakker J. Experiences of critically ill patients in the ICU. *Intensive Crit Care Nurs*. 2008; 24 (5): 300—313.
5. Granja C, Lopes A, Moreira S, Dias C, Costa-Pereira A, Carneiro A. Patients' recollections of experiences in the intensive care unit may affect their quality of life. *Crit Care*. 2005; 9:R96-R109.
6. Samuelson KAM. Unpleasant and pleasant memories of intensive care in adult mechanically ventilated patients—Findings from 250 interviews. *Intensive Crit Care Nurs*. 2011; 27 (2): 76—84.
7. Meriläinen M, Kyngäs H, Ala-Kokko T. Patients' interactions in an intensive care unit and their memories of intensive care: A mixed method study. *Intensive Crit Care Nurs*. 2013; 29 (2): 78—87.
8. Jones C, Backman C, Capuzzo M, et al. Intensive care diaries reduce new onset posttraumatic stress disorder following critical illness: a randomized controlled trial. *Crit Care*. 2010, 14:R168.
9. Cutlera LR, Hayterb M, Ryan T. A critical review and synthesis of qualitative research on patient experiences of critical illness. *Intensive and Crit Care Nurse*. Forthcoming 2013.
10. Evidence-based Medicine [Internet]. 2009 [cited 2013 Apr 15]. Available from: <http://www.medicine.ox.ac.uk/bandolier/painres/download/whatis/syst-review.pdf>
11. AM Price. Intensive care nurses' experiences of assessing and dealing with patients' psychological needs. *Nurs Crit Care*, 2004 May-Jun; 9 (3): 134-42.
12. Hunt JM. The cardiac surgical patients' expectations and experiences of nursing care in the intensive care unit. *ACCCN*.1999; 12(2) :47-53.
13. Rotondi AJ, Chelluri L, Sirio C, et al. Patients' recollections of stressful experiences while receiving prolonged mechanical ventilation in an intensive care unit. *Crit Care Med*. 2002; 30 (4): 746-52.
14. Adamson H, Murgoa M, Boylea M, Kerrb S, Crawfordb M, Elliotte D. Memories of intensive care and experiences of survivors of a critical illness: an interview study. *Intensive and Crit Care Nurse*. 2004; 20 (5): 257—263.
15. Wang K, Zhang B, Li C, Wang C. Qualitative analysis of patients' intensive care experience during mechanical ventilation. *J CLIN NURS*. 2008; 18: 183—190.
16. Hintistan S, Nural N, Öztürk H. Yoğun bakımda yatan hastaların deneyimleri. *Yoğun Bakım Hemşireliği Dergisi*. 2009; 13 (1): 40-46.
17. Leur JP, Schans CP, Loef BG, Deelman BG, Geertzen JHB, Zwaveling JH. Discomfort and factual recollection in intensive care unit patients. *Crit Care*. 2004; 8:R467-R473.
18. Granberg-Axell A, Bergbom I, Lundberg D. Clinical signs of ICU syndrome/delirium: an observational study. *Intensive Crit Care Nurs*. 2001; 17 (2): 72—93.
19. Capuzzo M, Valpondi V, Cingolani E, et al. Application of the Italian version of the intensive care

- unit memory tool in the clinical setting. *Crit Care*. 2004; 8 (1): R48-R54.
20. Özdemir L. Koroner yoğun bakımda kalan hastaların deneyimlerinin belirlenmesi. *Hemşirelikte Araştırma Geliştirme Dergisi*. 2010 ;1: 5-12.
 21. Granberg A, Engberg IB, Lundberg D. Patients' experience of being critically ill or severely injured and cared for in an intensive care unit in relation to the ICU syndrome. Part I. *Intensive Crit Care Nurs*. 1998; 14 (6): 294-307.
 22. Akıncı SB, Kanbak M, Güler A, Canbay Ö, Aypar Ü. Mekanik ventilatördeki hastalarda stres yaratan deneyimler. *Türk J Anesth Reanim*. 2007; 35 (5): 320-328.
 23. Roberts BL ,Cert IC, Rickard CM, Reynolds P. Factual memories of ICU: recall at two years post-discharge and comparison with delirium status during ICU admission – a multicenter cohort study. *J Clin Nurs*. 2007; 16 (9): 1669–1677.
 24. Sancaoğlu F, Akıncı SB, Dal D, Aypar Ü. Yoğun bakım hastalarında analjezi ve sedasyon. *Hacettepe Med. J*. 2005; 36: 86-90.
 25. Pennock BE, Crawshaw L, Maher T, et al. Distressful events in the ICU as perceived by patients recovering from coronary artery bypass surgery. *Heart Lung*. 1994; 23:323–327.
 26. Terzi B, Kaya N. Yoğun bakım hastasında hemşirelik bakımı. *Türk Yoğun Bakım Derneği Dergisi*. 2011; 1: 21-5.
 27. Puntillo KA, White C, Morris AB, et al. Patients' perceptions and responses to procedural pain: results from thunder project II. *Am J Crit Care*. 2001; 10(4): 238-251.
 28. Stanik-Hutt JA. Pain management in the critically ill protocols for practice. *Crit Care Nurs*. 2003; 23(2): 99-103.
 29. Bruster S, Jarman B, Bosanquet N, Weston D. Erens R, Delbanco TL. National survey of hospital patient. *BMJ*. 1994; 309: 1542–1546.
 30. Gêlinas C, Fortier M, Viens C, Fillion L, Puntillo KA. Pain assessment and management in critically ill intubated patients: a retrospective study. *Am J Crit Care*. 2004;13(2): 126-135.
 31. Jacobi J, Fraser G, Coursin D.B, et.al. Clinical practice guidelines for the sustained use of sedatives and analgesics in the critically ill adult. *Crit. Care. Med*. 2002; 30 (1): 119-141.
 32. Demir Y. Yoğun bakım ünitesinde ağrı deneyimi ve ağrının değerlendirilmesi: literatür incelemesi. *Düzce Üniversitesi Sağlık Bilimleri Enstitüsü Dergisi*. 2012; 2 (1): 24-30.
 33. Tunçay GY, Uçar H. Hastaların yoğun bakım ünitesinin fiziksel ortam özelliklerine ilişkin görüşleri. *Sağlık Bilimleri Fakültesi Hemşirelik Dergisi*. 2010; 33–46
 34. Daily Mail [Internet] [cited 2013 May 17]. Available from: <http://www.dailymail.co.uk/health/article-446387/Why-intensive-care-living-nightmare-patients.html>
 35. Jafar A. A, Nazih AT, Muayyad M. A. Patients' experience of being in intensive care units. *J CRIT CARE*. 2015; 30: 859.e7–859.e11.

Table 2. Characteristics of Studies Included in Review

| Study | Type of study | Participants | Time spent in intensive care | Sedation | Data collection (discharge/transfer from the) | Recalling the ICU n(%) | Outcomes n(%) |
|--------------------------------------|---------------|---|------------------------------|---|--|----------------------------------|---|
| 1- Granberg et. al. (1998) | Qualitative | First Meeting N= 31 Second Meeting N= 19 Age 25- 82 | >36 hours | Patients who were not sedated for a long time | 6 days- 6 weeks | 27 (54) recall intensive care. | Recollection: <ul style="list-style-type: none"> ▪ Patients recall pain, discomfort, ventilator support times, ET (Endotracheal) tube, and waking up times Patient Experiences: <ul style="list-style-type: none"> ▪ The nurses who did not communicate much with them and practiced the procedures without any explanations were evaluated as bad, while the nurses who took continuous care of them, talked to them, and treated them kindly were evaluated as good. ▪ Sleeping problems due to noise, uncomfortable beds, and fear ▪ Disturbance due to the equipment (mask, central catheter, SpO₂ prob, nasogastric catheter) |
| 2- Hunt (1999) | Qualitative | N=12 Age 51- 86 | - | - | In the hospital, after transfer from the ICU | 12 (100) recall pain experience. | Patient Experiences: <ul style="list-style-type: none"> ▪ Patients were focused on feeling the presence of the nurse ▪ Verbal and non-verbal communication as well as attention of nurses made patients feel better ▪ Some patients had communication problems because of the IT ▪ Disturbance due to noise ▪ 4 patients recall having hallucinations ▪ 3 patients recall experiencing pain; however, all patients expressed that nursing care helped ease their pain ▪ Patients reported experiencing fear, distress, anxiety, hallucination, and unexpected things. |

| | | | | | | | |
|-------------------------------|--------------------------|-------------------|--|---|---|---|---|
| 3-Rusell (1999) | Mixed | N= 298 Age >18 | >7 days | - | - 6 months after being discharged from the ICU | 71 (24) of the patients recall | <p>Recollection:</p> <ul style="list-style-type: none"> 126 (42) reported recalling just a little, 71 (24) reported full recollection. 3 (8) did not have any recollection. <p>Patient Experiences (n=217): 137 (63) felt the care of the health personnel, 29 (13) felt the technological support, 13 (6) felt the visits of their loved ones, 11 (5) felt the duration of the treatment, 11 (5) were disturbed by the noise, 9 (4) felt the presence of other patients, 3 (1,8) felt safe, 3 (1,2) felt fear.</p> <p>Sad Experiences (n=61); 15 (24) recall having difficulty in communicating with the nurse, 13 (21) recall lack of privacy, 10 (16) recall feeling fear, 10 (16) recall having pain and discomfort during treatment, 8 (13) recall being stressed due to noise, 3 (5) recall feeling lonely, 2 (3) recall not being respected.</p> |
| 4-Rotondi et al.(2002) | Prospective cohort study | N= 150 >18 | Patients who were subject to mechanical ventilator for at least 48 hours | - | After being transferred from the ICU to service | 100 (66.6) of the patients recall. | <p>Recollection:</p> <ul style="list-style-type: none"> 50 (48.5)% do not remember the intensive care or IT 112 (75) remember the intubation tube. <p>Patient Experiences: 75 (78.1) reported having difficulty in speaking, 73 (76) reported thirst, 49 (51) reported noise, 44 (45.4) reported depression, 43 (44.3) reported feeling fearful, 43 (44.8) remember being restrained, 41 (42.7) reported missing their spouses and friends, 38 (40.0) reported feeling as if something bad would happen, 38 (39.6) reported thoughts of death, 37 (38.5) reported not being able to sleep (insomnia), 37 (38.5) reported pain, 17 (17.7) reported having nightmares, 10 (10.3) reported headaches.</p> |
| 5-Leur et al. (2004) | Descriptive | N= 125 Age >18 | 2-133 days | + | In 3 days, after being transferred from the ICU | *Only the patients with recollection were included. | <p>Patient Experiences: 66 patients sources of discomfort; 27 (42) reported ailment due to IT 21 (32) reported hallucination, 14 (9) reported noise, 12 (8) reported pain, 9 (6) reported thirst, 9 (6) reported not being able to speak, 6 (4) reported feeling fear.</p> <p>In young patients experiencing physical discomfort due to pain was in a positive relationship with discomfortability.</p> |

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| 6-Capuzzo et.al. (2004) | Prospective study | N= 67 Age >18 | 3- 72 days | + | A week after, and 3 months after being transferred from the ICU | 187 (28.4) have clear recollection. | Patient Experiences: They reported remembering noise, lights, faces, IT tube, aspiration, darkness, nasogastric catheter, discomfort, confusion, pain, hallucination, nightmares and dreams. |
| 7-Adamson et.al. (2004) | Qualitative | N= 6 Age 57-83 | > 2 days | - | 6 months after being discharged from the intensive care | There are no patients with full recollection. | Patient Experiences: <ul style="list-style-type: none"> ▪ They reported remembering dreams and hallucinations, the nurses, noise, and the equipment ▪ They reported not feeling pain or anxiety ▪ One patient recalls a nurse treating her/him very kindly ▪ They reported there was no time orientation |
| 8-Granja et al. (2005) | Prospective study | N= 464 Age >18 | An avr. of 4 days | - | 6 months after being discharged from the intensive care | 13 (3.1) of the patients do not recall. | Recollection: <ul style="list-style-type: none"> ▪ 319 (77) remember the hospital Patient Experiences: <ul style="list-style-type: none"> ▪ 189 (93) reported that intensive care atmosphere was friendly and quiet, 62 (27) reported not getting enough sleep, 98 (30) reported having nightmares, ▪ The activities on which the patients stated to have distress were: 113 (81) aspiration, 127 (75) nasotracheal tube, 129 (71) worrying about the family, 121 (64) pain, 121 (64) immobility in bed, 114 (61) daily IV attempts, 111 (59) difficulty in communication, 93 (58) being dependent on the ventilator, 90 (56) urinary catheter, and 83 (54) noise and not being able to sleep at night. |
| 9-Akıncı et al. (2007) | Descriptive | N= 35 Age >18 | >24 hours | + | 24 hours after being transferred from the intensive care | - | Patient Experiences: 35 (100) the feeling of something bad would happen, 31 (90) headache, 30 (89) fear, 30 (88) losing loved ones, 29 (87.5) nightmares, 29 (83) thirst, 28 (80) pain, 28 (81) nervousness, 27 (78) feeling depressed, 26 (74) noise, 25 (71) distress, 24 (69) difficulty in swallowing |

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| 10 Hofhuis et al. (2008) | Mixed | n= 11 (Qualitative) n= 50 (Quantitative) Age 54- 82 | > 48 hours | - | 6-14 days after being transferred from the intensive care | 17 (34) recall | <p>Recollection:</p> <ul style="list-style-type: none"> ▪ 13 (26) reported no recollection while 19 (38) reported recalling just a little ▪ 19 (53) of the patients remember the intensive care as “pleasant”. 10 (28) as “unpleasant”, and 7 (19) as “definitely not nice”. <p>Patient Experiences:</p> <p>23 (46) reported pain, 20 (40) reported being disturbed by the noise, 24 (48) reported sleeping problems</p> |
| 11.Wang et al. (2008) | Qualitative | N= 11 Age 33-78 | 48- 303 hours | - | 3-14 days after being transferred from the intensive care | * The patients with recollection were included. | <p>Patient Experiences:</p> <p>1-Physical problems</p> <ul style="list-style-type: none"> ▪ Majority of the patients reported having pain during aspiration. <p>2-Psychological problems</p> <ul style="list-style-type: none"> ▪ Obscurity about the treatment and care ▪ Feeling despair, having hallucinations and nightmares, ▪ Fluctuations in the level of consciousness ▪ Depending on technology and the others for survival ▪ Anxiety after extubation <p>3-Self motivation</p> <ul style="list-style-type: none"> ▪ Most of the patients had thought they would heal faster with a positive attitude ▪ They reported that family support and visits were effective for recovery ▪ Some patients reported that the keen approach of the health personnel made them feel safe |
| 12.Hintis tan et al. (2009) | Descriptive | N= 52 Age 39-60 | 1-6 days | - | - | Intensive Care Awareness levels are above average | <p>Recollection:</p> <ul style="list-style-type: none"> ▪ Patients were aware of the atmosphere ▪ The score for recollection is low <p>Patient Experiences:</p> <ul style="list-style-type: none"> ▪ They had a high level of bad experiences ▪ Their satisfaction with the nursing is intermediate |

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| <p>13.Özdemir (2010)</p> | <p>Descriptive</p> | <p>N= 85 Age 22- 55</p> | <p>>4 days</p> | <p>-</p> | <p>-</p> | <p>The scale score of recollection of the intensive care is; 8,4 points (min: 4 - max: 20 points)</p> | <p>Patient Experiences:</p> <ul style="list-style-type: none"> ▪Score of the intensive care experience scale was: 46,1 (min:19-max: 95) ▪Scale score of being aware of the environment was: 19,4 (min:6- max: 30) ▪Bad experiences of intensive care: 7,5 (min:4- max: 20) ▪Score of the satisfaction with the nursing care in intensive care: 10,5 (min:5-max: 25) ▪The intensive care experiences of patients with pain were found to be more positive ▪Patients with pain had a clearer recollection of their intensive care experiences ▪The intensive care experiences of women were found to be more positive |
| <p>14-Samuelson (2011)</p> | <p>Qualitative</p> | <p>N= 250 Age 49- 72</p> | <p>>24 hours</p> | <p>+</p> | <p>3-5 days after the ICU transfer</p> | <p>203 (81) of the sample has recollection</p> | <p>Recollection: 178 (71) of the patients remember unpleasant experiences</p> <p>1- Unpleasant Experiences (n=178) 44 (25)% disturbing responses, 37 (21) noise, 33 (19) scary dreams, 30 (17) not being able to communicate,28 (16) uncertainty, 28 (16) unpleasant intensive care responses, 27 (15)% pain, 20 (11) fear and panic, 16 (9) bad hallucinations,14 (8) disrespectful staff, 12 (7) anxiety, 12 (7) despair, 10 (6) unable to sleep, 9 (5) disturbing daily procedures, 9 (5) fear of death.</p> <p>2- Pleasant Experiences (n=147): 57 (39) nice personality, 30 (21) respect and empathy, 19 (13) comforting nurses, 17 (12) feeling safe, 13 (9) care needs were met,10 (7) communication and explanations, 10 (7) hygiene.</p> |

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| 15- Meriläinen et al. (2013) | Mixed | n= 4 | An avr. of 13.5 + days | 3 and 6 months - after the discharge of patient | <p>Patient Experiences:</p> <p>1-Internal Experiences</p> <ul style="list-style-type: none"> ▪ Feeling pain, cold, and thirst ▪ Not being able to distinguish between being asleep or awake ▪ Thinking that they would not be able to make it out of the intensive care <p>2-External Experiences</p> <ul style="list-style-type: none"> ▪ Nurse responses ▪ Remembering visits of the loved ones ▪ Remembering communicating with the nurse |
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