FAMILY SATISFACTION WITH INVOLVEMENT OF FAMILY MEMBERS IN DECISION MAKING IN THE INTENSIVE CARE UNIT: A SCOPING REVIEW

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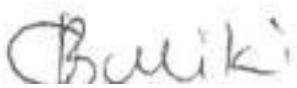
DECLARATION

I, Onalenna Baliki, declare that this research report is my own work. It is being submitted for the degree of Master of Science in Nursing at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.



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Signed at Johannesburg

On the 30th.....day of August....., 2021

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ABSTRACT

Background: Critical care delivery for critically ill patients in the intensive care unit (ICU) has evolved away from patient centered care to a family centered care, where families are considered partners in the care of their loved one. Families of critically ill patients admitted in ICU remain the integral part of the healthcare system therefore family members as surrogate decision makers should be involved in the decisions making. Decision making in the intensive care unit is often complex, involving frequent interactions between patients, their families, and health care professionals regarding basic and advanced life-support technologies.

Aim: The aim of the scoping review was to gather evidence related to family satisfaction with the involvement of family members in decision-making in the intensive care unit and to identify gaps and inconsistencies in the existing literature.

Design: A scoping review guided by Arksey and O 'Malley's framework was carried out. This framework includes identifying the research question, identifying relevant studies, study selection, charting the data and reporting the results.

Methods: A comprehensive literature search was conducted using CINAHL, Complete, Academic search and health science: nursing, MEDLINE, SCOPUS and PUBMED. All peer-reviewed studies published in English between 2010 and 2020 were retrieved.

Results: A total of 149 articles were screened, of which 24 were eligible for analysis, including 17 quantitative, 6 qualitative and 1 mixed method studies. Four main themes emerged from the scoping review namely: satisfaction, communication, involvement and support.

Conclusion: There was a significant gap in research on the active participation of family members in the clinical decision making process and factors influencing the family involvement in decision making.

Keywords*: decision making, family member, family involvement, family satisfaction, intensive care nurse, Intensive care unit.*

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LIST OF ABBREVIATIONS

ICU	Intensive Care Unit
SANC	South African Nursing Council
FCC	Family Centered Care
FS- ICU	Family satisfaction- intensive care unit
TSICU	Trauma and surgical intensive care
USA	United States of America
PCC	Population, concept, context
IPC	Interprofessional Collaboration
UK	United Kingdom
DM	Decision making
JBI	Joanna Briggs Institute

CHAPTER ONE

OVERVIEW OF THE STUDY

1.0 INTRODUCTION

This chapter provides an overview of the study. This includes the background of the study, problem statement, research question, aim and objective of the study, the significance of the study and operational definitions. A brief overview of the research methods and ethical considerations of the study will be discussed.

This scoping review sought to gather evidence related to family satisfaction with involvement of family members in decision making in the intensive care unit and to identify gaps and inconsistencies in the existing literature.

1.1 BACKGROUND OF THE STUDY

Admission in the Intensive care unit (ICU) due to critical illness usually comes unexpectedly, leaving the family members of the critically ill patient helpless and confused. It has the potential to disrupt the steady state of internal equilibrium usually maintained in the family unit. It can change the lives of the patient and those close to them in a minute, leaving little time for family adjustment (Morton & Fontaine, 2013). Family members of critically ill patients may experience stress, anxiety, depression and post-traumatic stress during admission and after their loved one has been discharged from ICU. The intimidating environment of the ICU, with its complex and technological equipment, adds to the distress and discomfort of family members. This is because they are not psychologically prepared for their family member's critical illness. Families may fail to adapt to the critical situation if they are not supported (De Beer & Brysiewicz, 2016; Majumdar & Bhole, 2018).

A review conducted by Azoulay *et al.* (2014), on Involvement of ICU families in decisions, 70% of families exhibited symptoms of anxiety and 35% depression in the first few days after admission. Another study conducted in Brazil, on symptoms of anxiety and depression in

family members of intensive care unit patients with population of 135 family members found that 28.9% of relatives experienced depression whereas 39.3% experienced anxiety after using Hospital Anxiety and depression scale (Fonseca *et al*., 2019). The involvement of family members in care and decision making in the ICU with effective communication helps to improve comprehension and to decrease anxiety and depression symptoms amongst family members (Azoulay *et al.,* 2014).

Critical care delivery in the intensive care unit (ICU) has evolved away from patient centered care to family centered care, where families are considered partners in the care of their relative. Therefore, families of critically ill patients admitted in ICU remain the integral part of the healthcare system. Gundo *et al.,* (2010) and Reeves *et al*.,(2015) concur with the above statement by emphasizing that families have a unique contribution towards healing and patient care as they act as advocates for the sedated and intubated patients. Family members play a key role as central hubs of information for their relatives since they are able to provide information about the patient because they know the patient better in the light of preferences, cultural and religious affiliations (Reeves *et al.,* 2015; Kingsinger, 2015). ICU nurses should respect and be sensitive to the cultural and religious therapies brought by the families of the critically ill patients.

Rodrigues (2011), emphasizes that family involvement is undoubtedly one of the biggest parts of patient therapy for the critically ill patients admitted in ICU. Patient-centered care has progressively advanced with nursing practice focusing on patient and family needs in synchrony to ultimately benefit the patient, encourage optimal recovery and promote positive outcomes. Holistic nursing care implies that the patient is not cared for in isolation but that the family is included in care and is cared for in an empathetic and compassionate manner.

Family centered care (FCC) framework recognizes that patients form part of a social structure and web of relationship therefore members of a health care team and families in the ICU (Huffines *et al*., 2013). During this time of critical illness, family members play an important role as surrogate decision markers because patients admitted in ICU lack decision- making capacity due to their critical state (Frivoid *et al.,* 2018; Kingsinger, 2015). However,

decision-making by family members may be influenced by emotional, moral and interpersonal considerations (White *et al*., 2012).

Family members of a critically ill patient form part of a team that engages in decision-making on behalf of the patient according to shared decision- making approach. Shared decision- making is whereby the health care professionals engage the patient and their family. Family members, as surrogate decision makers are responsible for making decisions like consenting for a procedure, treatment, care and can be asked to make end of life decision for the patient such as withholding or withdrawing therapy (Kryworuchko *et al.,* 2012). ICU nurses are supposed to help the family members in finding ways of coping with the unfamiliar environment as well as critical illness of their loved one. Family members will feel in control of the situation if ICU nurses assist them in identifying the available support systems. The identification and meeting of family needs and the involvement of families in the decision making process will reduce the anxiety and stress experienced by families. Family members who are satisfied with the care they receive experience less stress and are therefore able to provide better support to the patient (De Beer & Brysiewicz, 2016).

Family centered care approach and shared decision making model has been used in the ICU to promote family involvement in care and decision making in order to improve patient outcomes. However, the health care providers in ICU may face challenges in involving the family members due to the busy schedule, type of caring activity and family relationships. Health care providers in the ICU particularly nurses, suggested that family members should not be involved in every aspect of care and request availability of a clear policy to guide the extent of family involvement in the ICU (Fateel *et al*., 2016).

ICU clinicians are faced with the responsibility to make clinical decisions concerning the patient care. Decision making in the intensive care unit is often complex, involving frequent interactions between patients, their families, and health care professional regarding basic and advanced life-support technologies. Even though the principle of patient autonomy is emphasized in most countries, critically ill patient admitted in the ICU are not capable of participating in the decision making process due to their critical status. Family members of a critically ill patient form part of a team that engages in decision- making on behalf of the patient according to shared decision- making approach.

Clinical decision making in the ICU should be collaborative with the family member acting as the patient's advocate (Goldfarb *et al.*, 2017). FCC uses the elements of respect and communication which may improve overall quality of care in the ICU (van Mol *et al*., 2016). Communication has been found to be the most important need for the family members of a critically ill patient in ICU (Salis *et al.,* 2016; Kohi *et al.,* 2016). Providing family members with accurate information on diagnosis, prognosis and treatment of the patient may lead to lower level of anxiety and positively influence the satisfaction of care (Salis *et al.,* 2016; Frivold *et al.,* 2018).

Extensive research has been done in identifying and understanding the family needs in the ICU but some of these needs remain unmet by the health care professionals which results in dissatisfaction of the family members (Holden *et al.,* 2002; Schmollgruber & Bruce, 2002; Stricker *et al.,* 2007; Hansen *et al.,* 2016; Gundo *et al.,* 2014; De Beer and Brysiewicz, 2017). Family satisfaction with care and decision making in ICU is an important indicator to evaluate the quality of care provided by the health care professionals in the ICU, therefore it is important to measure family satisfaction with decision making in the ICU. The level of family satisfaction with care in the ICU indicate how well the perceived needs of family members of critically ill patients are met by the health care professionals (Clark *et al.,* 2016).

Studies on family members in the ICU have focused mostly on dynamics of care including family needs and coping, end of life decision making and communication. Literature has established that meeting the family member's basic needs in the ICU such proximity, honest information; reassurance and support facilitate effective coping mechanisms in family members when dealing with critical illness (Fateel *et al.,* 2016; Nolen, 2013; de Beer & Brysiewicz, 2016). Several studies have centered their research on family involvement during specific events such as end of life decision making, family conferences, family presence in resuscitation and family participation during rounds (Kryworuchko *et al.,* 2012; Kodali *et al.,* 2014; Reeves *et al.,* 2015; Kleinpell *et al.,* 2019).

Studies found that effective, consistent communication with family members of critically ill patients is one of the most important family needs in the ICU (Huffines *et al.,* 2013; Fateel *et*

al., 2016; Reeves *et al.*, 2015). Family meetings or conferences has been proposed as a measure in the ICU to increase communication thereby improving family member's satisfaction with participation in the decision making process (Huffines *et al.*, 2013; Kodali *et al.*, 2014; Azoulay *et al.*, 2014). In the study done by Hwang *et al.* (2014), in the United States of America (USA) found that families who did not participate in a single family meeting during their patient's admission in the ICU were less likely to feel complete control over patient care while those families who managed to participate in a formal meeting were likely to be completely satisfied with communication.

Most family members of the critically ill patient in the ICU are not satisfied with communication, they feel that they do not receive a full information about the patient which might hinder their participation in the decision making process (Fateel *et al*., 2016; Reeves *et al*., 2015; Kryworuchko *et al.*, 2012). In Malaysia, Othman *et al.* (2016) surveyed the family members after they have received information booklets during the ICU admission of their patient and found significance of increase in family satisfaction level regarding the decision making process compared with the group who received the usual information. In addition, the study done in USA found the association between the presence of a family meeting and increased satisfaction with the process of medical decision making (Kodali *et al.*, 2014. This indicates that the structured communication program can be utilized in the ICU to improve communication with family members during decision making process.

Findings from recent studies show that family members were highly satisfied with the overall care than their involvement in decision making (Frivold *et al*., 2017; Khoi *et al.*, 2016; Majumdar *et al.*, 2018; Clark *et al.*, 2016; Hansen *et al.*, 2016). However, improvements are still required in timely and appropriate communication to family members and family involvement in decision- making (Clark *et al*., 2016). Therefore, this study intends to address the gap in literature by examining family satisfaction with involvement of family members in decision making in the intensive care unit.

1.2 PROBLEM STATEMENT

Decision making in the intensive care unit is often complex, involving frequent interactions between patients, their families, and health care professionals regarding basic and advanced life-support technologies. Even though the principle of patient autonomy is emphasized in

most countries, critically ill patients admitted in the ICU are not capable of participating in the decision making process due to their critical status. Family members of critically ill patients form part of a team that engages in decision- making on behalf of the patient according to shared decision- making approach.

Decision making quality in the ICU is often considered substandard due lack of proper implementation of principles of shared decision making model which involves information exchange, deliberation and supportive consensus building between the health care professionals and patient's families (De Beer & Brysiewicz, 2016).

The involvement of family members in decision making and the family members perspective to ICU decision making process differ in various countries due to cultural background, religious beliefs and the country's health policies and regulations. In order to understand the level of involvement of family members in the ICU decision making process from a global perspective, this scoping review seeks to gather evidence from primary studies on family satisfaction with involvement of family members in decision making in the intensive care and to identify gaps and inconsistencies in existing literature.

Following the framework of Arksey and O'Malley (2005), the first stage of the scoping review process aimed at identifying the research question. The "**PCC**" mnemonic was used as a guide to ensure a focused research question. This mnemonic stands for the Population, Concept, and Context. In this study, the mnemonic was denoted:

Population: Family members

Concept: Satisfaction with involvement of family members in decision making

Context: Intensive Care Unit

The following research question guided the scoping review: ***What is the available literature on family satisfaction with the involvement of family members in decision making in the intensive care unit?***

1.3 AIM OF THE STUDY

The aim of the scoping review was to gather evidence related to family satisfaction with involvement of family members in decision making in the intensive care**.**

1.4 OBJECTIVES OF THE STUDY

The objectives of the study were:

- To describe family satisfaction with involvement of family members in decision making in the intensive care unit.

- To identify key concepts, gaps and trends in literature to guide practice and future research

1.5 SIGNIFICANCE OF THE STUDY

This study intends to obtain an understanding on family members' satisfaction with their involvement in decision- making. Studies in family satisfaction with involvement of family members in decision- making could help in identifying specific challenges faced by families from a global perspective. It is envisaged that evidence from this review will help in understanding the family members' satisfaction with their involvement in decision making in the ICU. Similarities and differences on family members' satisfaction on their involvement in decision making across countries, regions, cultures and individual ICUs will be drawn. This might project areas for further research and could bridge the gap in information, communication and involvement in decision-making in intensive care units. A platform for the implementation of strategies aimed at enhancing family centered- care which in turn could improve the clinical outcomes of patients can be created.

1.6 OPERATIONAL DEFINITIONS

Definitions for the purpose of the study were as follows:

- **Intensive care unit**

Intensive care unit refers to the unit in the hospital with specialized nurses and is equipped with high technology for monitoring care and treatment of patient with life threatening conditions (Morton & Fontaine, 2013). In this study, intensive care unit refers to specialised unit in the hospital with specialised equipment where critically ill patient are cared for by specialised health care professionals.

- **Critically ill patient**

Critically ill patient refers to a patient admitted in the ICU due to life threatening illness or injury that may result in significant disability or mortality" (Bennet *et al.,* 2016). For the purpose of this study, a critically ill patient will be a patient admitted in ICU with a life threatening illness or injury.

- **Intensive care nurse**

A person who has undergone, nursing education and training and is registered with the South African Nursing Council (SANC, 2005). Intensive care or critical care nurses are nurses who have undergone additional training to deal with actual and potential life- threatening conditions in an intensive care setting (Alspach, 2006). In this study intensive care nurse refers to a qualified nurse with or without a speciality in intensive care nursing working in the intensive care unit.

- **Family member**

A family is defined as a group of people that may be made up of partners, children, parents, aunts, cousins and grandparent related by marriage, blood or adoption (Sharma, 2016). In this study family member refers to the partner or spouse, parent, grandparent, adult child, adult grandchild (aged above 18 years) or significant other who is involved in the decision making process on behalf of the patient in the ICU.

- **Family Satisfaction**

Family satisfaction can be defined as fulfilling the needs and expectations of family members whilst their loved ones are admitted into ICU due to a critical illness (Rodrigues, 2011; Aart *et al.*, 2014). In this study; family satisfaction refers to the overall satisfaction of family members with their involvement in decision making when their loved one is admitted in the ICU.

- **Decision-making**

The healthcare team provides information to the families in order to allow them to participate in making decisions pertaining to the patient (Stricker *et al.,* 2007).

In this study, decision making refers to decisions made by family members of patients admitted in the ICU.

1.7 OVERVIEW OF METHODOLOGY

A scoping review guided by Joanna Briggs guidelines (Peters *et al*., 2015) was used in this study. A scoping review is an exploratory study that systematically maps the literature available on a topic, identifying key concepts, theories, sources of evidence and gaps in the research (Peters *et al*., 2015). This review was organized according to a framework proposed by Arksey and O'Malley (2005) which was further enhanced by the work of Levac *et al*., (2010) and the Joanna Briggs Institute (2017). The five stages followed are summarised in table 1.1 below.

A scoping review was chosen because it will provide information about key concepts on a topic in the existing literature, identify gaps in the literature, and serve as a basis on which future primary research or review can be conducted (Gagliardi *et al.*, 2016). The review was conducted to identify literature that addresses the review objectives. All studies published between January 2010 and June 2020 were included in the study. The researcher reviewed primary qualitative, quantitative and mixed method studies published in peer-review journals.

Table 1.1 Outline of scoping review framework

Stage	**Description**
Stage 1:	Identifying the research question
Stage 2:	Identifying relevant studies
Stage 3	Study selection
Stage 4.	Charting the data.
Stage 5	Collating, summarising and reporting the results

1.8 ETHICAL CONSIDERATIONS

Prior to the commencement of the study, the research proposal was presented and peer-reviewed for input from the Department of Nursing Education, School of Therapeutic Sciences, Faculty of Health Science, at the University of the Witwatersrand. An approval was

obtained from the Health Sciences Postgraduate Research Committee. Ethics waiver was obtained from the Human Research Ethics Committee (Medical).

1.9 LAYOUT OF THE STUDY

The layout of the study report chapters were organized based on the scoping review frame work proposed by Arskey and O' Malley's (2005). The research report will consist of five chapters.

Chapter One: Overview of the study

Chapter Two: Literature search and data collection

Chapter Three: Charting of data

Chapter Four: Presentation and discussion of results

Chapter Five: Summary of the study, implications and limitations

Table 1.2 Summary of the layout of the study.

Chapter	Purpose	Application
Chapter1:Identification of research question	Clarifying and linking the purpose and research question	Answer the research question" *What is the available literature regarding family satisfaction with the involvement of family members in decision making in the intensive care unit?*
Chapter 2: Literature search and data collection	Identify and collect all relevant literature sources to answer the research question	Searching of PubMed, CINAHL plus, MEDLINE, Academic Search Complete, Health Source: Nursing and Google Scholar. Hand search from relevant nursing
Chapter 3: Charting of data	Extract data and determine the methodological rigour	Use valid data extraction tools to extract data

Chapter 4: Presentation and discussion of results	Capture the breadth and depth of the topic and contribute new understanding	Report the result to demonstrate chain of evidence to support the conclusion
Chapter 5: Summary of study, implications and limitations	Present and discuss the synthesized findings in relation to research literature, practice and policy	The findings will be discussed in relation of literature, strength and limitation of the study and implication for practice highlighted

1.10 SUMMARY

This first chapter presented an overview of the study, which included the background, problem statement, aim and objectives of the study, significance, operational definitions, overview of the study, ethical considerations and the layout of the study.

The next chapter discusses the literature search and data collection stage as used in the scoping review process.

CHAPTER TWO

LITERATURE SEARCH AND DATA COLLECTION

2.1 INTRODUCTION

The purpose of this chapter is to provide a brief overview of the scoping literature review as a method and discuss the literature search process as used in this study.

2.2 SCOPING REVIEW PROCESS

A scoping review is an exploratory, non- experimental research design that systematically maps available literature and determines the scope or coverage of a body of literature on a given topic, identifying key concepts and gaps in the research (Munn *et al.,* 2018). The scoping review approach enhances the overview or mapping of the evidence of available literature of topic of interest (Munn *et al.,* 2018).

This study sought to map evidence in the literature available on family satisfaction with family members' involvement in decision making in the intensive care unit. The study intended to identify analyses and synthesize result from research studies to map the available literature on family satisfaction with decision making in the Intensive care unit. The scoping review was guided by Arksey and O'Malley's framework (2005) enhanced by Levac Colquhoun and O' Brien (2010).

Scoping reviews can be conducted to map a body of literature with relevance to time, location, source, and origin (Peters *et al.,* 2015). As stated in chapter one of this study, Arksey and O'Malley's (2005) five-stage framework underpinned the approach for this scoping review. The researcher identified the research question, identified relevant studies, selected studies, charted the data, and collated, summarized, and reported the results. The data were entered in a data extraction sheet (**Appendix A**) adopted from the Joanna Briggs institute (The JBI, 2015). The framework adopts a rigorous process of transparency, enabling replication of the search strategy and increasing the reliability of the study findings.

Figure 2.1 below summarizes the sequential steps of a scoping review:

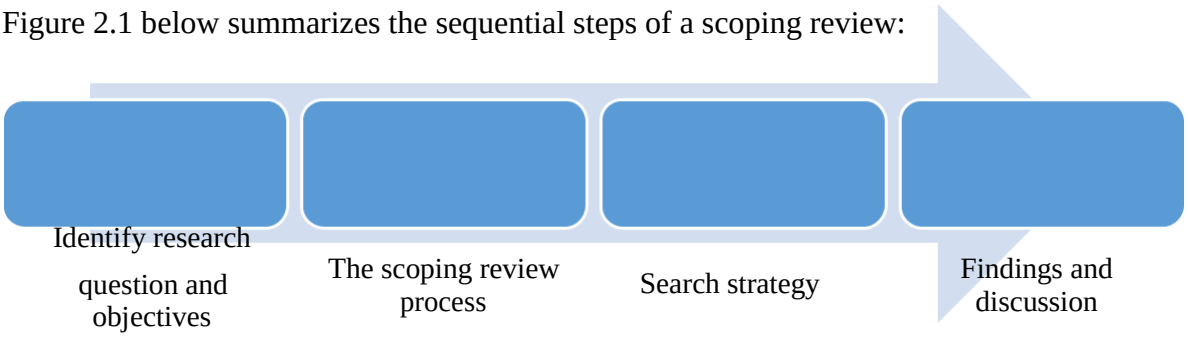


Figure 2.1: The four steps of the scoping review

2.3 Literature search

Literature search is systematic search of studies (published or unpublished) to identify relevant articles on a specific topic. Systematic literature searching is regarded as a critical component of the research review process. The literature should be comprehensive and requires the use of bibliographic databases searching and supplementary search methods (Cooper *et al.*, 2018).

The comprehensive literature search is crucial since it enables the researcher to avoid missing key studies and minimizes bias (Cooper *et al.*, 2018). In this literature search the researcher used electronic databases, manual hand search from specific journals and the reference list from the eligible articles. The target population referred to all previous studies that focused on family satisfaction with family members' involvement in decision making in intensive care unit. The sample which is accessible population referred to those articles that the researcher obtained after a completing the literature search using eligibility criteria, selected electronic database and key words.

The literature search process was explained which include search methods, electronic databases used, supplementary search strategies and eligibility criteria used in identifying the relevant articles for inclusion in the review.

2.4 SEARCH METHODS

2.4.1 Eligibility criteria

The formulation of inclusion criteria should be guided by the central focus of the study and maintains clear congruency between the title of the study, objectives, questions and inclusion

criteria (The JBI, 2015). The criteria for sampling the literature should representative of the sample of interest to ensure the reliability and validity of the review result. In this review, the central focus of the research study was taken into consideration which included family satisfaction, family members of patients admitted in ICU, involvement in decision making and Intensive care unit.

Studies published in English in peer-reviewed journals over a period of ten years were included. Literature reviews, dissertations, editorials and letters to the editor, case reports, discussion papers, and grey literature were excluded.

Table 2.1: Eligibility criteria

Criteria	**Inclusion criteria**	**Exclusion of criteria**
Type of study	Peer reviewed full-text research articles with abstracts Qualitative, quantitative and mixed methods	Literature reviews, editorials, books reviews and dissertations
Population	Family members	
Concept	Satisfaction with involvement of family members in decision making	
Context	Intensive care unit	Neonatal ICU, Pediatric ICU and all non- critical care setting
Language	English	Any other language
Publication date	January 2010 to June 2020	Before 2010 and after June 2020

2.4.2 Information sources and search strategy

The preliminary search was done prior to the detailed search to identify and define the search terms or words and search strings to be used in the literature search. The main concepts used during literature search were family satisfaction, decision making, involvement and intensive care unit. A scoping review was then undertaken to retrieve relevant literature sources over a

10- year period. The researchers planned to contact authors of primary sources when required, but as search progressed this was not deemed necessary.

The following methods were used for literature search and literature collection:

i) Articles were obtained from electronic database accessed through the University of Witwatersrand library
ii) Some articles were obtained from hand search of selected intensive care journals and relevant search engines.
iii) Article search from reference list of articles that were obtained

Data gathering started in July 2020 and ended in November 2020. The list of publications obtained from the databases were printed and reviewed to exclude articles that did not meet the inclusion criteria as well as duplicates. The titles were reviewed first followed by an appraisal of the abstracts if the titles were not clear enough. Full texts were used to investigate the authors and country in which the study was conducted.

2.4.2.1 Databases

The literature search requires a selection of many literature sources and the use of wide number of databases to enhance broader literature search and identity relevant articles. For the selection of databases used in this research study, the researcher consulted the librarian and the supervisor for the expertise.

The literature search was completed using the following electronic databases: PubMed, SCOPUS and EBSCO Host databases (CINAHL complete, MEDLINE, Academic search and health science: Nursing). These six databases were selected in this review because it was anticipated that they were likely to contain relevant studies on the phenomena of interest. PubMed is known to include articles over 200 million citations from MEDLINE and other life science Journals for biomedical articles dated back to 1950s.

CINAHL complete contains cumulative index for nursing and Allied health, health source: nursing provides scholarly full text Journals focusing in many medical disciples health sources and academic search complete contains interdisciplinary full text for the therapeutics

health science. SCOPUS has a broader coverage, with the largest abstracts and citation database for research literature with a large part of EMBASE included.

2.4.3 Search terms and search strings

The search terms and words were formulated based on the inclusion and exclusion criteria to enable the search to retrieve current knowledge and literature on the subject of interest in this review. The search words were formulated out of the main concepts which were family satisfaction, involvement in decision making and intensive care unit. The databases used in the literature search recognized the keywords selected. The search terms were framed by the researcher in consultation with the librarian and the supervisor. The preliminary search trial was conducted using the search words "family satisfaction, decision making and intensive care unit". The Boolean operators "AND" and "OR" were used to connect the search words in the review to broader or narrow the search result. For instance: "family" OR "relative" OR "next-of kin" AND "satisfaction" AND "involvement" OR "participation" AND "decision making" AND "intensive care unit" OR "critical care unit". The search strings used in the study are displayed in the Figure 2.1 below.

Figure 2.1: Search string used in the study

("family" OR "relatives" OR "next of kin")
AND
("satisfaction'')
AND
("involvement" OR "participation")
AND
("decision making'')
AND
("intensive care unit'') OR ("critical care unit'')

The researcher used the search string for each database included in the study to search literature. The search filters, as mentioned in the inclusion and exclusion criteria were used for each search. Initially the filters used were date limit and language. The results of each database search were documented and saved. The researcher searched through all databases (CINAHL complete, MEDLINE, Academic search complete, health source: nursing,

SCOPUS and PubMed) to retrieve relevant articles using similar search words and strings. During the search, the Boolean terms ALL FIELDS, TITLE, TITLE/ABSTRACT and KEYWORDS were used as they were provided in the search.

Secondly, the complement literature search using hand search was done to identify relevant articles that may have been missed during a database search. In this study, the intensive care and nursing journals used in hand search include Journal of Advanced Nursing, Journal of Clinical nursing, Nursing in Critical Care Journal and the South African Journal of Nursing.

Lastly, the researcher used the reference list of articles retrieved in the literature search process to identity additional articles. The reference list of articles was scanned and copied for search in Google scholar to search for relevant article to include in the study.

2.4.5 Supplement search methods

The Google search engine was also used to search and retrieve articles that the research missed in the search process. The researcher searched using the full title “family satisfaction with involvement of family members in decision making in the intensive care unit”.

2.4.6 Documenting the search

The literature search was done separately for each database and the outcome was recorded. The eligibility criteria, search filters and search terms guided the each literature search. The search filters were limited to date and language.

Table 2.2: Summary of literature search

DATABASE		SEARCH STRING	NUMBEROF ARTICLES
PubMed		(“family” OR “relatives” OR “next of kin” [All fields]) AND (“satisfaction” [All fields]) AND (“involvement” OR “participation” [All fields]) AND (“decision making’’ [All fields]) AND (“ intensive care unit”) [All fields] OR (“ critical care unit’’ [All fields])	19
SCOPUS		TITLE-ABS-KEY((“family” OR “relatives” OR “next of kin”)) AND TITLE-ABS-KEY ((“SATISFACTION”))ANDTITLE-ABS-KEY((“involvement” OR “participation”)) AND TITLE-ABS-KEY((“decision making”)) AND TITLE-ABS-KEY((“intensive care unit” OR “critical care unit”))	42
EBSCO host	CINAHL complete	(“family” OR “relatives” OR “next of kin”) AND (“satisfaction’’) AND (“involvement” OR “participation”) AND (“decision making’’) AND (“ intensive care unit’’ OR “critical care unit”)	11
	Academic search complete	(“family” OR “relatives” OR “next of kin”) AND (“satisfaction’’) AND (“involvement” OR “participation”) AND (“decision making’’) AND (“ intensive care]unit’’ OR “critical care unit”)	12
	MEDLINE	(“family” OR “relatives” OR “next of kin”) AND (“satisfaction’’) AND (“involvement” OR “participation”) AND (“decision making’’) AND (“ intensive care unit’’ OR “critical care unit”)	12
	Health source :nursing	(“family” OR “relatives” OR “next of kin”) AND (“satisfaction’’) AND (“involvement” OR “participation”) AND (“decision making’’) AND (“ intensive care unit’’ OR “critical care unit”)	3
Hand searched Journals	Nursing in critical care		5
	Journal of advanced nursing		1
	Journal of clinical nursing		2

2.4.7 Search outcome: Result from Electronic search

The literature search was done using the search strategy which included electronic database and hand search. A total of 149 articles were obtained (111 from electronic database, 38 articles from Journal hand search and reference list). This is clearly illustrated in table 2.2 which illustrates the summary of the literature search result. The 149 articles obtained from the initial search outcome were subjected to further scrutiny by two independent reviewers. This time the inclusion and exclusion criteria were strictly followed.

2.4.8 Selection and Screening process

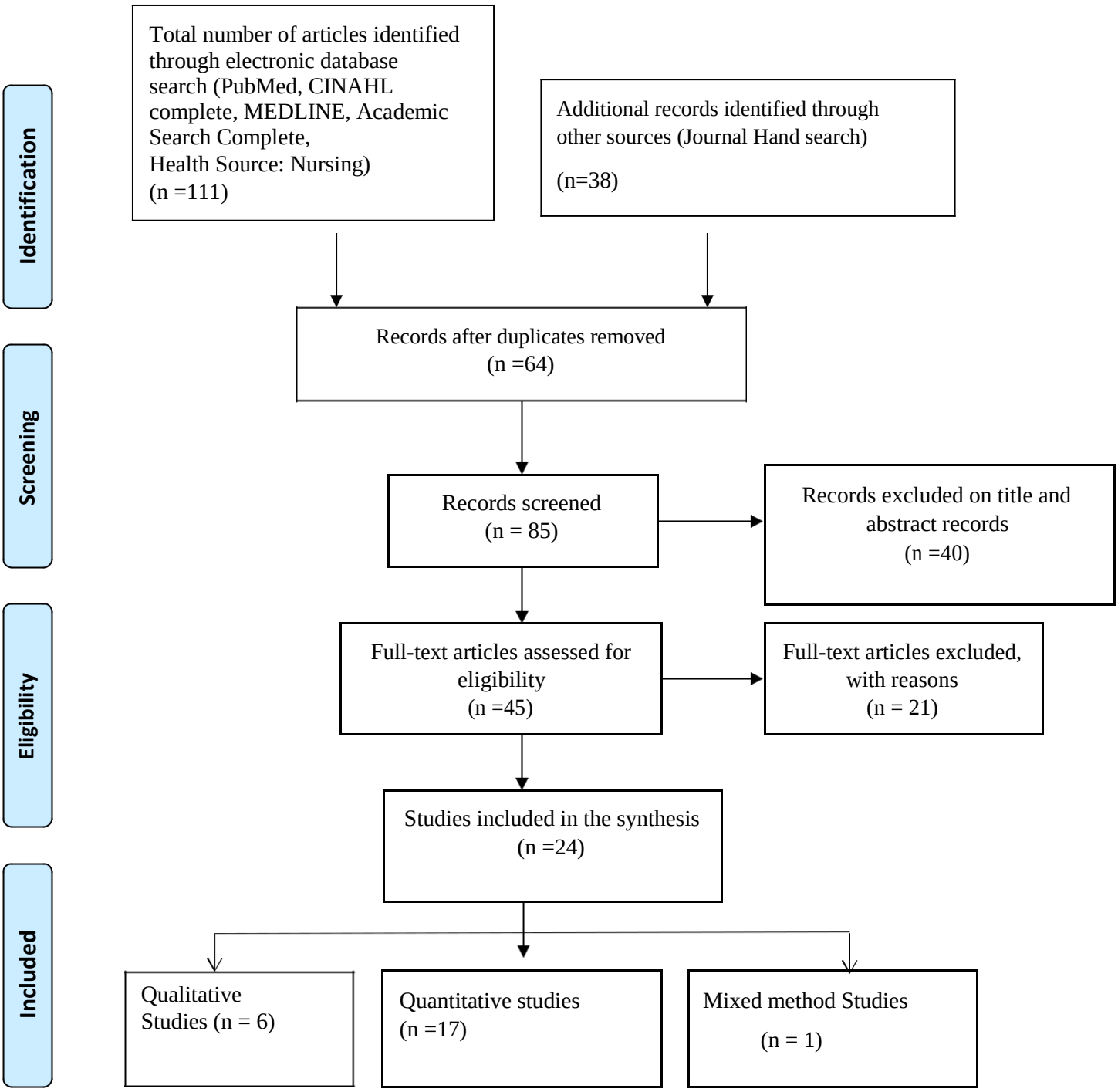
The selection of articles obtained from the literature search conducted based on the general selection criteria for inclusion. These selection criteria were applied to the titles and the abstracts of the articles and this was done to identify the sources relevant in answering the research question. The general selection criteria used in thus study included the following:

i) tittle of articles screening
ii) removal of duplicates
iii) abstracts and
iv) full text reading for article inclusion

All articles obtained in the literature search were screened by two independent reviewers (OB and NK). The title of each article was critically analysed for further inclusion in the study. The researcher went further to read the abstract of the articles whenever the title of the study fell within the inclusion and exclusion criteria. In some instances the title and the content of the abstract of the article were different, so both the title and the abstract were screened in order not to exclude relevant articles. The researcher removed duplicates as the title of articles were screened.

The remaining articles from initial selection were subjected to second stage of screening where two independent reviewers (OB and NK) screened the full text and the articles were chosen for inclusion in the study, when they met the inclusion criteria. The scoping review Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) flow diagram was used to report and map the searching process.

Figure 2.2 JBI PRISMA Flow Diagram



2.5 REASONS FOR EXCLUSION

In this scoping review, the selection and the screening process of articles for inclusion in the study were based on the inclusion and exclusion criteria. The inclusion and exclusion criteria were well formulated by the reviewers prior to commencement of the selection and screening process. The researchers strictly followed the criteria during the decision making process of excluding other studies from the study. Articles were initially excluded once their titles were found to be irrelevant to the subject of interest. Duplicates were excluded when the title were screened independently. Studies published in other languages apart from English were also excluded. Some of the studies were conducted within the acute care and paediatric setting. These were also excluded. From a total of 149 eligible articles, 125 articles were excluded.

2.6 METHODOLOGICAL RIGOUR

It is documented that literature review should maintain the standard of methodological rigour as in any other primary research. A thorough and comprehensive literature search and search process described in detail has been found to minimize biases (Cooper *et al.*, 2018). The systemic bias and error are bound to occur at any stage of the literature review, so the researcher should prevent any source of threat to the validity to ensure scientific integrity while conducting a scoping review, thus reducing biases.

The researcher devised measures to ensure methodological rigour. For a comprehensive literature search, well-defined search strategies were used to enhance the rigour of the research review. These strategies were broad and well defined search terms and index databases formulated before search process. A wide range of electronic databases were used to ensure a comprehensive literature search (PubMed, SCOPUS and EBCO host databases). The supervisor and librarian were consulted for expertise to ensure a well-articulated plan for literature search. Hand searches from relevant databases and direct contact with researchers complimented the search process.

2.7 SUMMARY

This chapter described in brief a scoping review as a method. The literature search strategy stage of scoping review was also discussed in detail; this included the search methods, databases, and selection of strategies, eligibility criteria and documentation of search result.

Lastly, the methodological rigour ensured in this stage was discussed.

In the next chapter, the data evaluation will be described and discussed.

CHAPTER THREE

CHARTING OF DATA

3.1 INTRODUCTION

This chapter discusses the process of charting data which is also known as data extraction in the scoping review.

3.2 DATA EXTRACTION

Data extraction refers to a process in which the researcher searches and records relevant result from the individual primary literature to create a descriptive summary of the result which addresses the scoping review objectives and question of the review (JBI, 2015).

In this study, the data extraction meant that the literature obtained was summarized in a data matrix format which covered all key information from each study. The data extraction process or charting of the results was done using the JBI template study details, characteristics and result extraction instrument and data were coded throughout the process to ensure consensus. A pilot test was done using the data extraction instrument with three articles prior to commencement of the review and it was refined. The pilot testing was done to ensure the accuracy of the data collection instrument in capturing all relevant data required to answer the research question. The supervisor (NK) complemented the researcher to extract the relevant data characteristics using the instrument used.

The data matrix used to extract study key information included author, year of publication, country of origin, title of publication, study objectives, population, sample and sampling, data collection method and instrument and key findings. Table 3.1 summarises the studies included in this review. To minimise the risk of bias, the researcher extracted the data iteratively, while the research supervisor compared the table containing the provisional titles with the extracted data. The titles were finalised during a consensus meeting.

Data matrix

Table 3.1: Characteristics of included studies

	Author (s) Year, Country	Title of publication	Aim/ objective	Research methodology design	Population/ sample/ sampling method	Data collection method /instrument	Result / findings	Recommendation and limitation
1.	Fat eel and O' Neil 2016 Ireland	Family members' involvement in the care of critically ill patients in two intensive care unit in an acute hospital in Bahrain: the experiences perspectives of family members' and nurses.	To explore family members and nurses perspectives and experiences of family involvement in caring for patients in intensive care units	A descriptive exploratory qualitative study	6 family members and six nurses from two intensive care units of hospital in Bahrain. Purposive sampling method	Focused group interviews	-Critical care nurses reluctant to involve family in care, even though generally family members of critically ill patients were willing to Participate in care. - being part of caring practices was important for family members and desired to be involved. Caring for the patient helped family members maintain the family bonds and cohesiveness and helped minimize the disturbance imposed on the family unit following a family member s admission to the ICU -most participants reported that they were ignored and dealt with as if they did not exist. -active communication was found to be central to quality of patient care -family members did not feel they had received	Role clarification and the responsibility of the nurses and families are needed to ensure patient care adheres to international standards and sensitive to Islamic family values to ensure family centered care id practiced. Limitation

							full information about their family member. Family members considered themselves as a rich source of information related to the patient. -family members were not allowed to be around during the patients doctors round, they were left with insufficient information. -family members expressed the need to be supported by nurses -Major constraint for families to participate in the care was visiting restrictions. -Nurses acknowledged the importance of active communication, sharing information and supporting family and meeting their needs. -nurses requested a clear policy to guide the extent of family involvement and to ensure that standards were consistently adhered to.	The nature of the family relationship and characteristics were not examined in the study
2.	Kryworuchko *et al.*, 2012 Canada	A qualitative study of family involvement in decision making about life support in	To explore family involvement in decision about life support interventions in the intensive care unit study using a	Descriptive qualitative study	6 family members 9 health care professionals A purposive sampling	Face to face interview	-None participating Family members perceived that they had been involved in decision making to start mechanical ventilation or other intervention. -families had limited ability to describe their involvement in the decision making process. -families were most frequently involved in	-The values reported by families members may be similar within their 3 family units -family members

		the intensive care unit	critical incident technique to focus on specific case exemplar by participants.				Decision making just prior to decisions to withhold or withdraw life support and provide comfort care interventions but less routinely in decision to start life support interventions. -several barriers were identified to involving families in shared decision making in intensive care unit. -Family has a role as patient advocate according to shared decision making , despite that family members were unlikely to become engaged without health care professional making explicit the decision to be made and minimizing other barriers across the decision making process. -alternative options are rarely discussed with patients and their families	were limited in their ability to report on the desirability / undesirability of specific elements of the options.
3.	Reeves *et al.*, 2015 UK Canada	Interprofessional collaborations and family member involvement in intensive care units:	To explore the culture of interprofessional collaboration (IPC) and family member involvement in eight North	Ethnographic approach	56 Health care providers, family members Purposive sampling	Semi structured interview	-Family members were often engaged in discussion about the care of their relative, these include conversations about treatment, options, progress of care and end of life care. -family members reported that communication was not consistent between ICU staff making it difficult to maintain continuity. -family members found that on occasion poor	

		emerging themes from a multi sited ethnography	American intensive care units.				interprofessional communication made it difficult to obtain consistent information about their relative. Family members were the filter of clinical information about their relative between ICU staff. Due to the largely parallel nature of clinical work of ICU, family helped to connect staff in care of their relative. There was little involvement of family members and patients in rounds. Family members reported mixed feeling about the function and their participation in rounds ICU admittance policies affected the degree to which family members felt they could be involved in patient care.	
4.	Lind *et al.*, 2012 Norway	Family involvement in the end of life decisions of competent intensive care patients.	to explore how relatives of terminally ill, alert and competent intensive care patients perceive their involvement in the end of life	Qualitative study	11 family members	Semi structured interview	-The families viewed their presence as very important for the ,experiencing their role of primary role as supporting and protecting their relative throughout the illness and the decision making process -the families express a need for transparency and participation in the end of life care discussion and the experience a distinct sense of	

			decision making process				responsibility for the patient. -the ability of the family to support and protect the patient through decision making process depends on their degree of involvement in transparent communication between the clinicians and the patient. Two of six cases in our empirical data reveal that the family experienced complete openness, rooted in the autonomy of the patient.	
5.	Mitchell *et al.*, 2010 Australia	Family Centered Care—A way to connect patients, families and nurses in critical care: A qualitative study using telephone interviews	to describe families' experiences of providing physical care to their critically ill relatives with bed-side nurses' support	A qualitative research design	10 family members Purposive sampling	Interviews	-Having an ability to be involved in providing patient care that was structured around the patient and family member allowed them to feel more helpful and part of the situation. -families can collaborate with nursing staff in order to provide patient care and having the opportunity to select the type of care delivered was important to the family members. -The partnering with nursing staff allowed families to feel better able to communicate more broadly with the nurses. -The nurses' ability to engage and support family members also promoted improved communication.	-No gender balance -Member checking was not performed -This study examined family members' experience of their participation, but did not include either the patient's or the nurse's

								experience.
6.	Kisorio & Langley, 2016 South Africa	End-of-life care in intensive care unit: Family experiences	To elicit family members' experiences of end-of-life care in adult intensive care units.	A descriptive, exploratory, qualitative design	17 family members Purposive sampling	Semi-structured interviews	Most family members were not satisfied with communication and information sharing, family members felt let out did not know exactly what was going on and what to expect. Family members wanted to be emotionally supported. Family members reported that they were not involved in the discussion and decision making process about the transition to palliative care rather they were just told about the decision. Family members felt that they knew about patients preference , so they wanted to act as their advocates whilst they were vulnerable, and needed to be involved in the discussion and decision making process	Generalization of the findings cannot be done because it is qualitative study
7.	Kodali *et al.*, 2014 USA	Family experience with intensive care unit care: association self-reported conferences	To examine whether family members who reported that a family conference occurred had higher satisfaction	Retrospectiv e cohort study	453 next of kin Purposive sampling	Questionnaire survey FS-ICU24	-The satisfaction scores in the domain of decision making were significantly higher for families who reported family conferences occurred. -the families who reported attending family conference were more satisfied with decision making in the ICU.	-The study was performed in Quaternary care only -the response rate of 55.6% relative low

		and family satisfaction	than who did not report that conference was held				There is an association between the presence of family meeting as reported by family members and increase satisfaction with the process of medical decision making.	-The study examined only association not relationship -the study used self-report of family conference
8.	Frivold *et al.* , 2017 Norway	Family members satisfaction with care and decision making in the intensive care units and post stay follow up needs –a cross-sectional survey study	To explore family members satisfaction with care and decision making during intensive care units stay and follow up needs after the patient discharge or death	Cross sectional survey	Survey 123 family members	Questionnaire FS-ICU24	-Family members were more satisfied with the treatment and care for the patient, but less satisfied with care of the family members and ICU staff communication skills. -the subscale FS- decision making showed a mean of 64 .8 (SD 26.3). -Family members of patient who died during stay were more satisfied with support and inclusion in in decision making compared with family members of survivors.	-The response rate relatively low was 47% -the assessment of satisfaction with acre after such a long time can also be influenced by other aspect of life such grief or heavy burdens which may disturb the initial impression

9.	Janardhanlyengar *et al.*, 2019 India	Family satisfaction in a medical college multidisciplinary intensive care unit (ICU)-How can we improve?	To ascertain the level of family satisfaction of care and their involvement in the decision making process of their patients treatment.	Observational study	100 family members	Questionnaire FS-ICU24	-Satisfaction with overall care was 65.31±23.62 (FS-ICU/Care). -Satisfaction with decision making process was 73.06±22.154 (FS-ICU/ DM). -Individual factors which contributed to lower scores were management of pain and agitation of the patient, waiting room atmosphere and emotional support	-The questionnaire was translated verbatim in the local language. -association with demographic data of respondents was not established.
10	Lam *et al.* , 2015 Hong Kong	Intensive care unit family satisfaction survey	To examine the level of family satisfaction in a local intensive care unit and its performance in comparison with international standard	Questionnaire survey	961 adult family members	Questionnaire FSICU	-Mean score for subscale FS-ICU decision making domain was 78.6 which were low compared to Canadian multicenter databases of 82.6 indicating that there was a room for improvement. - satisfaction with overall intensive care unit care was 78.0 -greatly affected family satisfaction includes the ICU environment, agitation management, and	-Most respondents completed the questionnaire while their sick family member was still under the care Questionnaire

							communication between health care workers and families. These are all potentially amenable to improvement -the sub score for decision making were higher than overall care which is in contrasts to the other countries.	completed before ICU discharge may not reflect the entire ICU experience.
11	Hwang *et al.*, 2014 USA	Assessment of satisfaction with care among family members of survivors in a neuroscience intensive care unit.	To explore family satisfaction with care in an academic Neuro ICU and compare with concurrent data from same hospital's medical ICU.	Observationa l study	106 family members	Questionnaire FS- ICU 24	-About 75 % of family members were completely satisfied with 9 of the 10 aspect decision making covered in the survey. -52.6% of family members participated was completely satisfied with inclusion in decision making and 44% support during decision making. Family members who reported no participation in any formal family meeting were less likely to feel completely satisfied with the concern and caring them as family members by ICU staff.	-it was a single center study -The study used the survey with many questions in a relatively a small cohort families.
12	Ferrando *et al.*, 2019 United kingdom	Family satisfaction with critical care in the UK: a multicecentre	To assess family satisfaction with intensive care units(ICUs) in the UK using the family	Prospective cohort study	Purposive sample 6380 family members	Questionnaire FSICU24	-family members of ICU non survivors had higher scores for overall and satisfaction with decision making process domain then family members of survivors -decision making domain family satisfaction measured with FS –ICU 24 questionnaire was	-it is not uncommon for continuous measure to be skewed when assessing

		cohort study	satisfaction in intensive care unit 24 item (FS-ICU-24 questionnaire -to investigate how characteristics of patients and their family members impact on satisfaction.				high -Satisfaction with the domain of decision making process domain score : family members of ICU survivors 75.0 And family members of ICU non survivors 87.1 -The high levels of family satisfaction among family members of ICU non survivors may be attributed to greater involvement of the family in end of life care decision making.	satisfaction. -excluding family members who had spent less than 24 hours on ICU. -there were differences in the case mix and outcome of patients between those who had at least one family member recruited and those who did not leading to potential bias in the result.
13	Maxim *et al.*, 2019 USA	Family satisfaction in the trauma and surgical intensive care unit: another	To describe and analyze the result of family satisfaction survey in the TSICU.	Prospective observational study	Convenience sample 131 family members	questionnaire modified version FSICU24	-The mean score for FS –ICU decision making domain was 79.3 -Mean scores (±SD) were 80.6±26.4 for satisfaction with care -the family members scored higher t (91.8) in the item of satisfaction with the amount time to	-the result may not reflect the overall population of patients and family members in the TSICU as

		quality measure.					make decisions and ask questions. -the family members scored lower (70.66) in the item of satisfaction with frequency of communication with doctors. -in terms of inclusion in decision making process family members score 76.29 while for support in decision making 74.22.	we used a sample of convenience -the respondents submitted their response while the patients were still in the TSICU.
14	Othman *et al*., 2016 Malaysia	The effects of information booklets on family satisfaction with decision making in an intensive care unit of Malaysia	To test the effects of information booklets on family satisfaction with decision making around the care of critically patients in an intensive care unit.	Quasi – experiment Pre and post -test design	Convenience sample 84 family members	Questionnaire FSICU 24 QOC Descriptive and inferential analysis	-Decision making pre-test score intervention group was 22.7 while post- test score was 29.6, showing an increase in the satisfaction while scores from control group shows decrease in satisfaction. -this indicates that the structured communication program is effective for family members. -the findings showed significant differences between the mean values in the control group, indicating that family members were satisfied with decision making in the ICU. -Family members were satisfied with their decision-making experience because there was good communication and support, enabling them to achieve the effective care for their family	The use of information booklets can be an evidence practice for all the nurses and should be included in updating clinical practice guidelines Limitation The study depended on personalized self-

							member	report data which might have been influenced by a social desirability bias and lack of cooperation from family members due to the short visiting hours.
15	Huffines *et al.*, 2013 Maryland	Improving family satisfaction and participation in decision making in an intensive care unit	To develop and implement an evidence based communication algorithm and evaluate its effects in improving satisfaction among patients families	Pre and post-design	Convenience sample 41 family members	Questionnaire	Statistically improvements were noted for how often they were able to participate in decision making -13 family meeting resulted in decision about treatment limitation -demonstrated that evidence based structured communication algorithm may be one approach to improve ICU family members satisfaction with participation in decision making.	-the generalization of result is limited by the project evaluation design, the small convenience sample and the single sit for data collection. -the ICU culture of this setting may have influenced result

								of the project. -the algorithm may require adaptation to the needs, resources, clinicians and culture of a specific ICU.
16	Jensen *et al.*, 2017 Denmark Netherlands	Satisfaction with quality of care for patients and families: the euro Q2 project	To examine assessments of satisfaction with care in a large cohort of Danish and Dutch family members and to examine the measurement characteristics of the euro FS-ICU.	Cross sectional Survey	1077 family members 573 Denmark 504 Netherlands	Questionnaire Euro FS-ICU Descriptive and inferential analysis	-Inclusion in decision making process the Dutch rating were higher than of the Danish -items with fewer "excellent" endorsements and suggesting he need for improvement were consistency information, inclusion and support in decision making processes. -Those who chose "Fair" or "Poor" when asked about inclusion in the decision making processes, 63% stated that they were not involve enough -72% reported that they had enough time to have their concerns addressed and questions answered when major decision were made while 9% did not have enough time.	-SAPS scores were only available for approximately 70% of the sample and from 62% of the ICUs, so the generalizability of these findings may be limited. -some eligible family members were left out during the study

								period, due to ICU staff forgetting to mention the study to them. -The effect of ethnicity is not examined.
17	Clark *et al.*, 2016 Massachusetts	Measuring family satisfaction with care delivered in the intensive care unit	To assess the feasibility of the selected tool for measuring family satisfaction and to make recommendations that is based on the results.	Descriptive survey	40 family members	Questionnaire FS-ICU24	-The mean satisfaction with decision-making was 72.03% ,indicating that most family members reported good to very good satisfaction with decision-making -the satisfaction with care subscale was 72.24%	-Collecting data related to satisfaction with the care while a patient remains hospitalized can potentially pro-vide false-positive results -the self-selected family member responding may not have represented the collective view of all family

								members
18	Hagerty *et al*., 2015 USA	Assessment of satisfaction with care and decision-making among English and Spanish-speaking family members of neuroscience ICU patients	To determine if there were any differences between English-speaking and Spanish-speaking family members of patients in a neurological ICU	Single center prospective study	74 family members	Questionnaire FS-ICU24 Descriptive analysis	-Both groups were satisfied in the domain of care -Spanish-speakers were statistically less satisfied in the domain of decision-making than English-speakers -Spanish speakers were less satisfied with process of getting information and felt less supported in their decision making. -about 73 % English speaker and 77% of Spanish speakers reported inclusion in decision making process -family members expressed dissatisfied with communication and giving consistent honest information in both groups.	-The studies' small sample size makes it difficult to make recommendations about the satisfaction of all English and Spanish-speaking family members.
19	Hwang *et al.*, 2014 Massachusetts	Consistency of communication among intensive care unit staff as perceived by family members of	The hypothesis was that intensive care unit (ICU) families frequently perceive that they have received inconsistent	Prospective cohort study	124 family members	Questionnaire FS-ICU 24	-31 respondents reported at least one episodes of inconsistent information during their relatives' admissions. -38 % reported experiencing these inconsistencies multiple times during admission. -74.2 % of family members indicated that their experiences of discordant information occurred within the first 48 hours of the patient arriving in	-

		patients surviving to discharge	information from staff about their relatives and that these inconsistencies influence abilities to make medical decisions, as well as satisfaction				the ICU. - Family members did not perceive that inconsistencies of information made the decision making difficult. Only 9.7% of family members reported that they experienced difficult in making Decision.	
20	Sundararajan *et al.*, 2012 Australia	Determinants of family satisfaction in the intensive care unit	To explore the degree and determinants of satisfaction of family members of patients being cared for in an Australasian intensive care unit	Prospective observational study	84 family members	Questionnaire	-Highest scores recorded were for communications with nursing staff and for courtesy, respect and compassion. -lowest scores were for frequency of doctors' communication. -Families who had documented meetings with the social worker or the medical staff were less likely to report dissatisfaction with their support in the ICU. -family members were less satisfied with their interactions with the medical than with the nursing staff. -the family members median score was 8.0 of involvement in decision making.	-Only families of patients who had spent 48 hours or more in the ICU were enrolled in this study. -population was predominantly Caucasian and from a single centre, thus limiting generalization of result to other

								hospital or cultural setting.
21	Schwarzkopf *et al.*, 2013 Germany	Family satisfaction in the intensive care unit: a quantitative and qualitative analysis	To assess family satisfaction in the intensive care unit (ICU) and areas for improvement using Quantitative and qualitative analysis	Prospective cohort study	215 family members	Questionnaire FS-ICU	-Scores were 77.8 for FS-ICU decision making domain while for FS-ICU care was 78.6 - areas of improvement identified for family participation in the following items: ✓ inclusion of family in care and decision making , ✓ feeling included in the decision making process and ✓ feeling control over patient care -compassion and emotional support are important in the decision making process -shared decision making the primary model for family participation needs to be adapted to families' needs -families of ICU non survivors were more satisfied than families of survivors.	-The low response rate which raise the probability of response bias -findings were from a single center and cannot be generalized.
22	Jacobowski *et al.*, 2010	Communication in critical care: family rounds in the	-hypothesized that family attendance at structured interdisciplinary	Before-after study	227 family members	Questionnaire Survey FS-ICU	Families who attended family rounds rated excellent for how often the doctors communicated about your family members' condition showing improvement.	-A single-center study - Study included only English-

	Nashville (USA)	intensive care unit	family rounds would enhance communication and facilitate end-of-life planning (when appropriate).				Families who had the opportunity to attend family rounds reported much supported during decision making process. Family members reported that they were not satisfied with time given to address concerns and questions answered during decision making before and after attending family rounds	speaking patients.
23	Henrich *et al.*, 2011 Canada	Qualitative analysis of an intensive care unit family satisfaction Survey	To describe the qualitative findings from a family satisfaction survey to identify and describe the themes that characterize family members' intensive care unit experiences		880 family members	Questionnaire FS-ICU 24 Thematic analysis	-Family members expressed feeling excluded from discussions that the physicians were having about their loved ones. -The tone of the comments seems to reflect frustration and anger at the family's exclusion. - family members believe that they are able to handle the honest information about their patient and that full and realistic information about the situation better enables them to make treatment and end-of-life decisions and to cope with the patient's situation. 18% of respondents experienced positive comments about communication in the ICU.	-Inferences from our findings are limited by the sampling frame of our survey -Respondent characteristics were not evaluated to determine whether the respondents were representative of their sites
24	Maina *et al.*, 2018	Involvement of patients	To determine families	Descriptive cross	52 family members	In-depth interviews	-The majority of family members were involved in acquiring general information followed by	

	Kenya	families in care of critically ill patients at Kenyatta national hospital critical care units	involvement in the provision of care to critically ill patients in Kenyatta National hospital critical care units.	sectional study	Purposive sampling		consenting for surgical procedures -the female were more satisfied than males in the extent of involvement in the care of the critically ill patients. -family members were not satisfied with depth of information about the patient care -luck of full involvement of family member in all aspects of treatment for their patient was due to lack of knowledge on how and when to contribute to patients care. Families reported build up anxiety levels due to withholding of information by the nurses. -No policies to guide the involvement of families in critical care in Kenyatta National Hospital.	

3.3 Methodological rigour

Literature search forms a crucial part of the review. It is crucial to maintain methodological rigour throughout the research phases to reduce bias. Several strategies were followed to limit any threat to the validity and scientific integrity of this review (Tobin & Begley, 2004; JBI 2015).

. The measures are outlined below:

- A broad search strategy was outlined prior to the literature search. This included the main concepts of the review, key terms, eligibility criteria, literature selection process and documentation.
- Several databases were used to broaden the literature search. The use of less than three databases limits the search
- An experienced and qualified librarian was consulted during the literature search process for assistance and guidance.
- The researcher used a reliable and validated data extraction instrument developed by JBI and captured relevant features in each of the included articles as stipulated in the instrument
- The pilot test was conducted using the tool to ensure its accuracy in capturing relevant data.
- The two independent reviewers coded the content of the individual studies and the extracted data were further cross checked by two independent reviewers.

3.4 Summary

This chapter discussed the charting of data which is data extraction process and finally outlined the methodological rigour ensured at this stage.

The next chapter will present the results of the scoping review.

CHAPTER FOUR

PRESENTATION AND DISCUSSION OF RESULTS

4.1 INTRODUCTION

This chapter presents the results of the scoping review, the study characteristics as retrieved in the review process and a narrative description of the results. The discussions of the main findings will be provided and lastly, the chapter ends with a summary.

4.2 RESULTS

This review aimed at gathering research evidence on the family satisfaction with family members' involvement in decision making in the Intensive Care Unit. The initial search using five databases; PubMed, SCOPUS, CINAHL complete, MEDLINE, Academic search complete and Health Source: Nursing/Academic edition, for studies published in peer-reviewed journals from January 2010 to June 2020. There were 149 potentially relevant studies retrieved (111 from the electronic database search and additional 38 from hand search and reference list). Duplicates were discarded and irrelevant literature excluded based on title and abstract. Finally, 45 full-text studies were further assessed for relevance against the inclusion and exclusion criteria. Data extraction was finally done from 24 studies to answer the research question. The PRISMA diagram was used to map the result as indicated in chapter three.

4.2.1 Study characteristics

Key characteristics were extracted from each individual study included in the review based on the predetermined data extraction tool that was found to be useful in answering the research questions (**Appendix A**).

The following sections present the characteristics of the included studies.

4.2.1.1 Study location

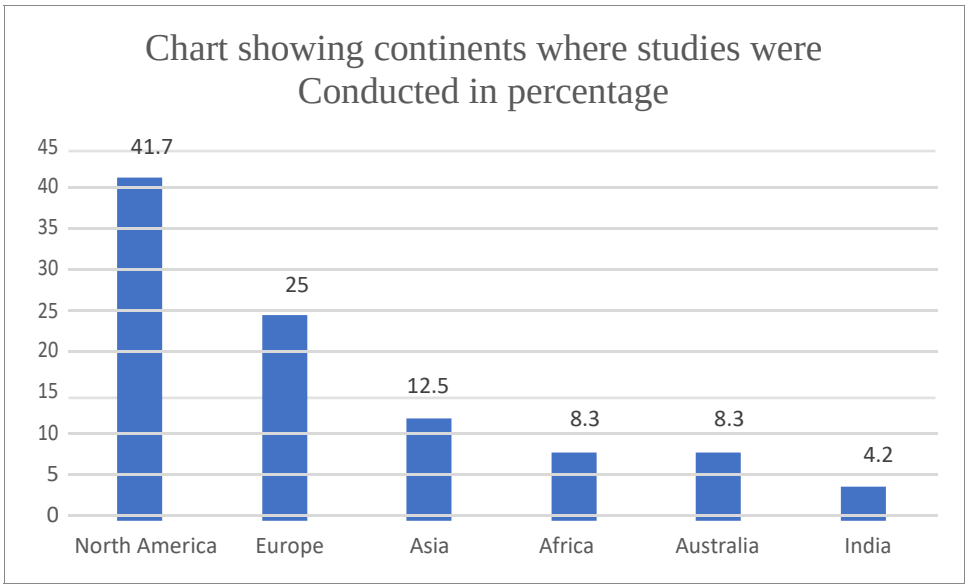
The articles obtained in the review presented data from studied conducted in the six different continents representing 17 countries with diverse cultural backgrounds. North America was

the leading continent with ten (n=10) studies; United States of American (n=7), Canada (n=3). The second continent was Europe with six (n=6) studies (Norway (n=2), UK (n=2) Germany (n=1), Denmark & Netherlands (n=1). The third continent was Asia with three (n=3) studies. Malaysia, Hong Kong and Bahrain had one study each. Australia had two studies (n=2) and the last two studies were from Africa (Kenya (n=1), South Africa (n=1). And India had one study.

Table 4.1 Summary of continents

Total	**24**
Study continent	**Number of studies (%)**
Africa	2(8.3)
Asia	3(12.5)
Australia	2(8.3)
Europe	6(25.0)
North America	10(41.7)
India	1(4.2)

Figure 4.1. Summary of continent where studies were conducted



4.2.1.2 Research method and study designs

Of the 24 articles included in this research review 17 (n=17) articles were quantitative, 6 (n=6) qualitative and (n=1) mixed methods. The quantitative studies predominantly used study designs such as prospective cohort and descriptive cross sectional with few articles using retrospective cohort, observational and pre- post study design. The qualitative studies used descriptive exploratory and ethnography study designs. The mixed methods study included cross sectional and in-depth interviews.

4.2.1.3 Study population, sample and sampling

The participants included in various studies were family members of critically ill patients admitted in the ICU (n=21) or health care providers (n=3). Sampling strategies used in the recruitment of the participants in most studies were purposive and convenience sampling. The sample size for each study ranged from 6 to 6 380 family members.

4.2.1.4 Participants characteristics

The studies reported that most participants were close family members including spouse, sons, daughter and significant other. Sampled family members were family members of critically ill patient admitted in the Intensive care unit. Demographic data revealed that most participants were females and few male family members participated. Two studies included intensive care unit health care providers and one study included intensive care nurses as study participants.

Table 4.2 Study participants

Participants	Total –N%
Total -N	24
Family members	21(87.5)
Family and nurses	1(4.2)
Health care professional/providers and family members	2(8.3)

4.2.1.4 Data collection and analysis

All the quantitative studies included in this review used a validated instrument during data collection. Descriptive and inferential statistical analysis was used. The qualitative studies in this review used mostly semi structured interviews to collect data; one study used focused group discussions. Most qualitative studies utilized thematic data analysis, one study utilized content analysis and two used both thematic and content analysis.

4.2.1.5 Study journals

This research review included (n=24) published studies, and these studies were published in different nursing and medical journals. Two (n=2) studies were published in each of the following journals: Critical Care Nurse, Critical Care Medicine, Journal of Critical Care, and American Journal of Critical Care. Each of the remaining studies was published in the Clinical Nursing Studies, American Journal of Hospice and Palliative Care and Nursing Ethics Journal. Table 4.3 summarises this information.

Table 4.3 Study distribution in various journals

Journal	Number of studies	country
Critical Care Nurse	2	United states of America
Critical Care Medicine	2	
Journal of Critical Care	2	United states of America
Clinical Nursing Studies	1	Spain
American Journal of Critical Care	2	United States of America
American Journal of Hospice and Palliative care	1	United States of America
Journal of Inter-professional Care	1	United Kingdom
Nursing Ethics	1	United Kingdom
Intensive and Critical Nursing Care	1	United kingdom
Nursing open Journal	1	
Indian Journal of Critical Care medicine	1	India

Hong Kong medicine Journal	1	Hong Kong
Journal of Neuroscience Nursing	1	United states of America
BMJ open(British Medical Journal Open)	1	United kingdom
Journal of Surgical acute care	1	United States of America
Journal of Young Pharmacists	1	India
Applied Nursing	1	
Anesthesia and Intensive Care	1	Australia
Intensive care medicine	1	Germany
American Journal of nursing science	1	United States of America

4.3 KEY THEMES

This scoping literature review provided evidence that most of the studies focusing on family satisfaction with family involvement in decision making in ICU in the last 10 years were conducted in North America, followed by Europe then Asia, Australia, Africa and lastly India.

Following a comprehensive analysis of the included studies, four themes emerged. They include satisfaction, communication, involvement and support. The highest-rated theme was satisfaction. The four themes that emerged in this study are summarized in table 4.4.

Table 4.4 Summary the themes

Theme	Sub-theme
1. Satisfaction	- Satisfaction with care - Satisfaction with decision making
2. Communication	- Consistency of information - Clarity and completeness of Information - Transparency
3. Involvement	- Involvement during patient care - Involvement during decision making
4. Support	- Informational support - Emotional support

4.3.1 Theme One: Satisfaction

Satisfaction of family members was the most investigated theme in this scoping review. Family satisfaction refers to opinions or perspectives of families towards the care and decision-making in the ICU. All quantitative studies used family satisfaction in the intensive care (FS-ICU 24) survey, a 24 item self-report that measures family satisfaction with care and decision making. This survey was developed by Heyland and Tranmer (2001). The qualitative studies utilized in-depth interviews to explore family perspectives with care and decision making in the intensive care unit.

4.3.1.1 Subtheme: Satisfaction with care

Family satisfaction with care was investigated by various authors who used both qualitative and quantitative methods. The focus of this review was to gather evidence on studies which looked at family satisfaction with involvement in decision making, however, this subtheme emerged because the FS-ICU 24 survey assesses satisfaction with care and decision making. This subtheme emerged from nineteen studies (Frivold *et al.*, (2017), Lam *et al.*, (2015),

Clark *et al.,* 2016; Janardhanlyengar *et al.,*2019; Ferrando *et al.,* 2019; Maxim *et al.* 2019; Jensen *et al.,* 2017; Hagerty *et al.,*2015; Sundararajan *et al.,*2012; Hwang *et al.*, 2014; Maina *et al.,* 2018; Kodali *et al.,* 2014; Henrich *et al.,* 2011; Schwarzkopf *et al.,* 2013; Fateel & O' Neil, 2016; Reeves *et al*., 2015; Kisorio & Langley, 2016; Mitchell *et al.,* 2010 & Lind *et al*., 2012).

This review revealed that family members rated the satisfaction with care with the mean score between 65.31 and 83 amongst the studies which used FS-ICU survey. This indicates that family members are not entirely satisfied with care rendered to their loved one in the intensive care unit. Some of the factors that emerged under this sub theme contributed to lower scores. These factors include dissatisfaction with pain management, agitation management, waiting room' s atmosphere, emotional support and communication (Janardhanlyengar *et al.,* 2019; Lam *et al.,* 2015). Family members reported that they desired to be involved or participate in the direct care of their loved one however, the critical care nurses were reluctant to involve families in the care (Fateel & O' Neil 2016; Kisorio & Langley *et al.,* 2016).

The evidence shows that involving families in patient care helped family members maintain the family bonds and cohesiveness. It also helped minimize the disturbance imposed on the family unit following a family member s admission to the ICU (Fateel & O' Neil 2016; Lind *et al*., 2012). In addition, in the study by Reeves *et al*. (2015) conducted in United kingdom with 10 participants also concurs that when the family members are involved in providing patient care structured around the patient, these helps the family member to feel more helpful and part of the situation.

4.3.1.2 Subtheme: Satisfaction with decision making

Family satisfaction with decision making was presented by nineteen several authors in this review (Frivold *et al.,* 2017; Lam *et al.,* 2015; Clark *et al.,* 2016; Janardhanlyengar *et al.,* 2019; Ferrando *et al.,* 2019; Maxim *et al.,* 2019; Jensen *et al.,* 2017; Hagerty *et al.,* 2015; Sundararajan *et al.,* 2012; Hwang *et al.,* 2014; Kodali *et al.,* 2014; Henrich *et al.,* 2011; Schwarzkopf *et al.,* 2013; Huffines *et al.,* 2013; Othman *et al.,* 2016; Kisorio & Langley *et al.,* 2016; Lind *et al.,* 2012; Kryworuchko *et al.,*2012; Jacobowski *et al*., 2010& Hwang *et al.,* 2014).

It was found that amongst the quantitative studies, FS- ICU survey was mostly used to assess the satisfaction with decision making and family members rated decision making domain with the mean score between 64.8 and 80.6 (Frivold *et al.*, 2017; Lam *et al.*, 2015; Clark *et al.*, 2016; Janardhanlyengar *et al.*, 2019; Ferrando *et al.*, 2019; Maxim *et al.*, 2019; Jensen *et al.*, 2017; Hagerty *et al.*, 2015; Hwang *et al.*, 2014; Kodali *et al.*, 2014; Henrich *et al.*, 2011; Schwarzkopf *et al.*, 2013; Othman *et al.*, 2016; Jacobowski *et al.*, 2010; Hwang *et al.*,2014).

In this review, it was revealed that there are factors that influence family satisfaction with involvement in decision making. This was evident in the Norwegian study, with the population of 123 relatives found that family members of a patient who died during the stay were more satisfied with support in decision making compared to family members of ICU survivors (Frivold *et al.*, 2017). Family members expressed dissatisfaction with communication during the decision-making process in the ICU; they felt that there is a need for transparent, honest and consistent information (Lind *et al.*, 2012; Frivold *et al.*, 2017). In the United States of America (USA), Hagerty *et al.*, 2015 found that both English and Spanish speaking respondents were not satisfied with the way they were supported during the decision-making process.

4.3.2 Theme Two: Communication

The second theme that emerged in this review is the communication between the patients, health care providers and families in the ICU. Communication and information emerged from the literature as an area that needs improvement in the ICU. Communication was investigated by four (n=4) qualitative studies (Lind *et al.*, 2012; Reeves *et al.*, 2015; Kisorio & Langley, 2016; Fateel & O' Neil 2016). Ten quantitative studies investigated this theme (Frivold *et al.*, 2017; Maxim *et al.*, 2019; Jensen *et al.*, 2017; Hagerty *et al.*, 2015; Hwang *et al.*, 2014; Sundararajan *et al.*, 2012; Huffines *et al.*, 2013; Othman *et al.*, 2016: Ferrado *et al.*, 2019; Jacobowski *et al.*, 2010; Henrich *et al.*, 2011). Only one mixed methods study explored communication (Maina *et al.*, 2018).

4.3.2.1 Subtheme: Consistency of information

These review revealed that information need was perceived important by the family members in the intensive care unit, hence they reported less satisfied with the consistency of information they received about their patient (Reeves *et al.,* 2015; Kisorio & Langley, 2016; Frivold *et al.*, 2017). A prospective cohort study by Hwang *et al.* (2014) conducted in Massachusetts with 124 participants found that family members reported one or multiple episodes of inconsistent information during their relatives' admissions.

It was also found that poor or inconsistent communication between the ICU health care professionals made it difficult for family members to obtain consistent information about their relatives (Reeves *et al.,* 2015). In this review, family members were not satisfied with frequency of communication with physicians; their perception were that it is difficult to be addressed by the doctor (Maxim *et al.*, 2019; Hwang *et al.*, 2014).

4.3.2.2 Subtheme: Clarity and completeness of information

The second subtheme that emerged from communication is clarity and completeness of information received by family members in the ICU. Fateel and O' Neil (2016) conducted a study in Ireland and found out that most family members of the critically ill patient in the ICU are not satisfied with the communication. They felt that they do not receive full information about the patient which might hinder their participation in the decision making process. In addition, a Canadian study by Henrich *et al.* (2011), revealed that family members believe that they are able to handle the honest information about their patient and that full and realistic information about the situation enables them to make better treatment and end-of-life decisions and to cope with the patient's situation.

In Kenya, Maina *et al*. (2018), conducted a study to determine families' involvement in the provision of care to critically ill patients in Kenyatta National hospital critical care units. Their result also revealed that family members were not satisfied with the depth of information about the patient care, and families reported buildup of anxiety levels due to withholding of information by nurses.

4.3.2.3 Subtheme: Transparency

The third sub theme was transparency in communication. Family members were not allowed to be around during the doctors rounds and these left them with insufficient information (Fateel & O Neil, 2016; Kisorio & Langley, 2016). Family members expressed the need for transparency therefore they desire to know exactly what going on with their patient and these may enhance the ability of the family to support and protect the patient through decision making process (Linda *et al*., 2012).

4.3.3 Theme Three: Involvement

Family members often assume the responsibility of surrogate decision-maker over the decision-making process about the choices of the diagnostics, treatment and life support care. The family involvement in care and decision making was investigated by five (n=5) qualitative studies (Kryworuchko *et al.,* 2012; Lind *et al.,* 2012; Mitchell *et al.,* 2010; Kisorio & Langley 2016; Fateel & O' Neil, 2016). Six quantitative studies (n=6) quantitative studies investigated involvement (Frivold *et al.,* 2017; Hwang *et al.,* 2014; Ferrando *et al.,* 2019; Maxim *et al.,* 2019; Jensen *et al.,* 2017; Schwarzkopf *et al.,* 2013). Lastly, one (n=1) mixed-method study by Maina *et al*. (2018).

4.3.3.1 Subtheme: Involvement during patient care

It was evident from the scoping review that family members are willing to be involvement in their patient care and they believe that the patients could still hear and feel their presence even if they were not able to see or talk (Kisorio and Langley, 2016; Fateel and O' Neil 2016). In addition, in the study by Mitchell *et al.,* (2010) where 10 participants were interviewed, a family member reported that providing the care demonstrate love and attachment to the patient. Involving family members in direct patient care may pose some challenges on the family members such as fear of doing such activities with their ill relative surrounded by machines, attached to so many lines and tubes without the nurse to direct them(Kisorio and Langley, 2016).

As stated in the study by Fateel and O' Neil (2016) involvement of families in the care for the patient helped family members maintain the family bonds and cohesiveness which may help in minimize the disturbance imposed on the family unit following a family member's admission to the ICU.

4.3.3.2 Subtheme: Involvement during decision making

This review revealed that family members perceived that they had not been involved in decision making to start mechanical ventilation however most frequently involved in decision making just before decisions to withhold or withdraw life support and provide comfort care intervention (Kryworuchko *et al.,* 2012; Lind *et al.,* 2012; Kisorio & Langley, 2016:). Linda *et al.,* 2012).

The quantitative studies examined inclusion in decision making through identifying and describing the inclusion of family members in the decision making in the ICU and comparing perspectives of family members of non-survivors and survivors (Frivold *et al.*, 2017; Hwang *et al.*, 2014; Ferrando *et al.,* 2019; Maxim *et al.*, 2019; Jensen *et al.*, 2017), and they found that family members of non-survivors were more satisfied with inclusion in decision-making than families of ICU survivors.

4.3.3 Theme Four: Support

The least researched subject of family involvement in decision-making in the ICU is the support given to families during decision-making. In (n=9) quantitative studies, and (n=3) qualitative study sought to identify and explore the support given to family members during the clinical decision-making process (Frivold *et al.,* 2018; Hwang *et al.*, 2014; Maxim *et al.*, 2019; Jensen *et al.*, 2017; Mitchell *et al.*, 2010; Kisorio & Langley, 2016; Fateel and O' Neil, 2016; Schwarzkopf *et al.,* 2013; Henrich *et al.*, 2011; Othman *et al*., 2016, Huffines *et al.,* 2013 and Jacobowski *et al*., 2010).

4.3.4.1 Subtheme: Informational support

Support with information emerged in this review as an important need for family members caring for a relative in the ICU. It is the responsibility of health care providers (doctors and nurses) in the ICU to ensure that this need in met. This review revealed that most family members were not satisfied with the information given about their patient; they reported that nurses withhold information from them as nurses could not share some information (Maina *et al*, 2018; Kisorio & Langely, 2016).

Several authors demonstrated that the use of information booklets, family meeting as well as having family rounds may improve the communication in the ICU which may enable family members to receive full information about their patient (Othman *et al*., 2016; Huffines *et al.*, 2013; Jacobowski *et al*., 2010).

4.3.4.2 Emotional support

Emotional support emerged as the second theme under support. Family members expressed some form of distress due to the critical illness of their loved one as they were not prepared for it therefore they desired to be emotionally supported particularly by the nurses (Kisorio & Langely, 2016; Fateel & O' Neil, 2016). In this review, family members reported the need to be reassured about the comfort care given to the patient and the nurses to be patient with them during this critical time (Fateel and O' Neil, 2016).

4.4 DISCUSSIONS OF MAIN FINDINGS

The literature search involved searching the databases of PubMed, SCOPUS, CINAHL complete, MEDLINE, Academic Search Complete, and Health Source: Nursing (2010-2020) The search terms: family, satisfaction, involvement, decision making and intensive care unit were used. The findings from this scoping review revealed that there is evidence of research studies conducted on family satisfaction with the involvement of family members in decision making in ICU. However, most of these studies were conducted in North America (n=10), Europe (n= 6) and Asia (n=3).

The review shows that the level of family satisfaction with involvement in decision-making can be improved when the ICU staff put in place some strategies to facilitate family participation in the decision-making process (Huffines *et al*, 2013). Communication and receiving information in the ICU emerged as an area that needs improvement because family members felt that it hinders their participation in the decision-making process (Fateel &O' Neil, 2016; Reeves *et al.*, 2015). These results are consistent with the results of an Australian study done by McLennan & Aggar (2020) where family members were not satisfied with the frequency of communication with both ICU nurses and doctors and was ranked second lowest ranked low in family satisfaction decision-making subscale. Family members should receive clear, honest and consistent information to enhance shared decision making process (McLennan & Aggar, 2020).

The scoping review findings have demonstrated that evidenced-based structured communication strategies are effective for family members to improve family members' satisfaction with participation in decision making (Huffines *et al.*, 2013; Othman *et al.*, 2016). An evidence-based structured communication algorithm was used to identify clinical triggers for family meetings in the study done Huffines *et al.* (2013) using a pre-post design. There were statistically significant improvements noted for how often the family members were able to participate in decision making where before the algorithm the score was 45% and after the algorithm was 68% (Huffiness *et al.*, 2013). Another study was done in Malaysia by Othman *et al* (2016)investigated the effects of information booklets on family members' satisfaction with decision making in ICU with the population of 84 family members, found that there is improvement in the FS-ICU decision making mean score pre-test score was 22.7 while the post-test score was 29.6.

A retrospective cohort study conducted in the USA with a population of 453 next of kin found that the families who reported attending the family conference were more satisfied with the decision making process in the ICU (Kodali *et al.*, 2014) and this confirms that the use structured communication program improves family satisfaction with decision making. In contrast, in the study done by Jacobowski *et al.* (2010) where family rounds were implemented to improve communication in the ICU found that family members reported that they were not satisfied with time given to address concerns and questions answered during decision making process before and after attending family rounds.

Another theme that was highlighted in this scoping review was involvement during decision making process. Even though family members assume surrogate decision-maker roles over the decision-making process about the choices of the diagnostics, treatment, and life support care of their loved one, they have expressed dissatisfaction when it comes to the timing of inclusion during decision making. In a qualitative study done in Canada by Kryworuchko *et al.* (2012)where 6 family members and 9 health care professionals were interviewed, family members expressed that they were not involved in decision making to start mechanical ventilation or other intervention however they were most frequently involved in decision making just prior to decisions to withhold or withdraw life support and provide comfort care interventions but less routinely in the decision to start life support interventions.

Family inclusion during the decision-making process particularly in end of life decision to withhold or withdraw life support made for critically ill patients was found to vary from active participation in the decision making process to acceptance of the physicians' decision or just receiving information of the physicians' decision (Lind *et al*., 2012). In a situation where the family members were just informed about the physician's decision to terminate treatment, families were unsure whether the patient was competent to decide considering the critically ill state of the patient and fluctuating level of consciousness (Lind *et al*., 2012). Similarly, in a South African study by Kisorio and Langley (2016) reported that family members were just told about the decisions made without being actively involved.

Family members of non-survivors were found to be more satisfied with inclusion in the decision-making process more than with family members of survivors (Hwang *et al*., 2014: Frivold *et al*., 2018). This can be attributed to the fact that family members of non-survivors are often involved in decision-making just before withhold or withdraw life support and provide comfort care interventions (Kryworuchko *et al.*, 2012). Also, the difference may be explained by the fact that some patients who are admitted in ICU can participate in the decisions and consent for procedures for themselves (Frivold *et al.*, 2018).

This review also highlighted the importance of support from nurses and doctors during the care and decision-making process which is crucial for the well-being of family members and their ability to participate in making decisions.

Family members require informational support as well as emotional support to assist them to cope with the critical illness of their loved ones.

The information need of the family members remain unmet, the family members were not satisfied with the consistency of information about the patient's condition and the completeness of the information (Schwarzfkop *et al.*, 2013: Fateel & O'Neil, 2016; Frivold *et al*., 2018). A South African study by Kisorio & Langley (2016), with a population of 17 family members found similar findings that family members were not satisfied with the information they received about their patient's progress.

In a qualitative study done in Ireland with a sample of six family members of a critically ill patient, family members highlighted that the nurses should have more patience when dealing with them during this critical time and support them emotionally (Fateel *et al.*, 2016). It is also emphasized that the ICU health care providers to have a thorough consideration of emotional impacts imposed by the admission of a family member in the ICU so that they may understand the family needs to be holistically supported (Fateel *et al., 2016*). Findings from the study by Kisorio & Langley (2016) concurs that those family members of critically ill patients need emotional support to cope, however, family members reported dissatisfaction with emotional support in the ICU.

A quantitative study done with a population of 215 in Germany found compassion and emotional support to be important particularly during the decision-making process and recommends that a shared decision-making model for family participation has to be adapted to family needs (Schwarzfkopf *et al.*, 2013). The study done by Blom *et al.*, 2013 in Sweden in which their aim was to explore participation and support as experienced by close relatives of patients at an intensive care unit confirms that support in the form of information sharing and emotional support is important for family members to enable them to participate in the decision making.

4.5 GAPS IN RESEARCH

4.5.1 Knowledge gap pertaining to family involvement in decision making

This scoping review identified a lack of research on the nature and extent of family involvement and active contribution in the clinical decision making process.

Family centered care and shared decision making models have been used in intensive care unit to optimize patient and family outcomes through collaborative partnership process with patients, families and health care providers(Mitchell *et al.,* 2010). However, findings from this review indicate that there is lack of research to investigate the active participation of family members in the clinical decision making process. Literature does not clearly reveal specific trigger to begin the process of involving family members in the decision making of their loved one in the ICU.

This was evident in this review where family members perceived that they had not been involved in the decision making to start the mechanical ventilation and other interventions (Kryworuchko *et al.,* 2012). Literature indicated that family members were frequently involved in decision making during end of life care where decision to withhold or withdraw life support care should be made (Kryworuchko *et al.,* 2012; Lind *et al.,* 2012; Ferrando *et al.,* 2019).

The literature also lacks research on the evaluation of factors that influence the partnership between the families and health care providers in decision making process in the intensive care unit. For future research there is a need for more exploratory research in to the nature and extent of family involvement in decision making process in the intensive care unit.

4.5.2 Knowledge gap pertaining to factors influencing the family involvement in decision making

This scoping review identified that factors influencing family involvement in decision making are largely under –researched. Literature revealed that researchers focused on relationship between family members and nurses (Mitchell *et al.,* 2010) and on inter-professional care in intensive care unit (Reeves *et al.,* 2015). Although relationships between nurses and family members are crucial during decision making process, but the socio-cultural, organizational, contextual factors that may shape the conditions for family involvement in decision making process in the intensive care unit are under-researched.

Literature on critical care identified few studies which investigated factors shaping the decision making process in the intensive care unit. Kryworuchko *et al. (*2012) study on family involvement in decisions about life support in the intensive care unit highlighted barriers or factors which interfered with involving family members in the shared decision making process. An ethnographic study examined unit cultures on inter-professional collaboration and family involvement (Reeves *et al.,* 2015). The literature on family involvement in decision making process in intensive care can be strengthened by conducting more research investigating broadly the socio cultural, organizational and contextual factors shaping the setting under investigation. Family members from different cultural backgrounds bring their own cultural beliefs, expectations and experiences when it comes to participation in the intensive care unit. In the study by Fateel and O'Neil (2016), it was evident that culture can shape how families perceive and conceptualize involvement in intensive care unit.

4.5.3 The need for methodological triangulation and ethnographic methods

In this scoping review, there were few studies that triangulated methodologically. Most of the studies used quantitative surveys or qualitative interviews as their sole data collection method. This methodological gap is evident in the family satisfaction literature where the researchers used FS- ICU survey as a data collection tool. The FS-ICU survey is used to understand the family satisfaction in the intensive care in the domain of care and decision making but surveys alone are unable to conclude about different aspects of care and decision ratings and they cannot outline the factors that influence family satisfaction.

Amongst qualitative literature, lack of data triangulation was a limiting feature considering the common use of interviews alone to investigate the family involvement and family satisfaction in the intensive care unit. Interviews may be useful to access the family experiences on decision making process within the ICU but the use of data triangulation can be valuable to strengthen the research outcomes and enable generalization of study result to the general population. Ethnographic approaches are used to examine the group of individuals in the setting where they live or work. It entails sustained observations and immersions within social setting (Creswell, 2012).

These ethnographic approaches can be valuable in providing additional rigour and quality to survey and interview based approaches, by revealing the social, cultural and professional processes that influence the family involvement within a given setting (Reeves *et al*., 2015).

There is a need for more research to be conducted using ethnographic approach in the intensive care units to develop an understanding of family involvement during decision making process.

4.6 SUMMARY

The chapter presented the results of the research review. The findings generated were presented according to the study characteristics, participants' characteristics and methodology. Key findings were discussed and finally gaps in research outlined and discussed.

The following chapter will include discussions of results, limitations and conclusion.

CHAPTER FIVE

SUMMARY OF STUDY, MAIN FINDINGS, RECOMMENDATIONS, LIMITATIONS AND CONCLUSION

5.1 INTRODUCTION

In this chapter, the summary of the study will be presented. This include summary of the main findings, potential limitations of the study, as well as implications and recommendations for future nursing research. Finally, the chapter will end with conclusion from the main findings.

5.2 SUMMARY OF THE STUDY

5.2.1 AIM OF THE STUDY

The aim of the scoping review was to gather evidence related to family satisfaction with involvement of family members in decision making in the intensive care and to identify gaps and inconsistencies in existing literature

5.2.2 OBJECTIVES OF THE STUDY

The objectives of the study were to:

- To identify available literature on family satisfaction with involvement of family members in decision making in the intensive care unit.
- To describe family satisfaction with involvement of family members in decision making in the intensive care unit.

5.3 SUMMARY OF MAIN FINDINGS

The scoping review sought to retrieve, map evidence and identify gaps in existing literature on family satisfaction with involvement of family members in decision making in the intensive care.

The study provides an understanding of the extent of evidence in existing literature on family satisfaction with family members in involvement in decision making in intensive care unit. This scoping review included 24 studies that met the eligibility criteria. The four themes that emerged include: satisfaction, communication, inclusion and support during decision making process.

5.3.1 Satisfaction

It was evident from the review findings that family satisfaction with decision making in the intensive care unit have been investigated. Most of these studies were conducted in developed countries. There is paucity of studies conducted in developing countries and in Sub-Saharan Africa. This gap implies that the diverse cultural backgrounds and the voices from Sub-Saharan Africa are unheard. In most studies, investigators used Family satisfaction ICU scale (FS-ICU) and used a quantitative method. Even though, there is some evidence that family members may be satisfied with involvement in decision making process from some of the studies in this review but more research should be conducted using qualitative and mixed method in order to understand family experiences and opinions with involvement in decision making in the intensive care unit.

5.3.2 Communication

Communication and receiving information was identified as one of the important component of family involvement decision making process and it was found to be one the area that needs improvement in ICU. It was also evident from studies that effective structured communication between the health care providers and families in the ICU is required to facilitate shared decision making process and improve family satisfaction with participation in decision making in ICU (Othman *et al*, 2016).

5.3.3 Involvement

It was evident from the review that family members assume the role of surrogate decision maker over the decision making process on behalf of their loved one who is critically ill in the ICU but their inclusion in decision making is not satisfactory.

It was evident from the review that families are mostly involved in decision making in ICU when decisions to withhold or withdraw life support and provide comfort care intervention are to be made.

5.3.4 Support

The scoping reviews findings revealed that families need emotional and informational support during decision making process (Mitchell *et al.*, 2010). It is very critical for families to receive appropriate support to enable them to make informed and sound decisions about diagnostics, treatment and life support care of their loved one. Few studies explored the support given to the family members during decision making process in ICU in this review.

5.4 LIMITATIONS OF THE STUDY

The following limitations identified in this review are worth noting:

The study included articles published in English language only. Therefore, this review missed potentially relevant articles published in other language. The literature search was limited to a 10 year period with published studies identified between January 2010 and June 2020. Research studies published before January 2010 and after June 2020 were not included in this review but they could have influenced and added value to the findings of this review. Literature search was conducted using only PubMed, SCOPUS and EBSCO host databases (MEDLINE, CINAHL, Academic Search complete, Health Source: Nursing). The grey literature was not included in this review. The articles that could not be accessed through the University of Witwatersrand online library databases were excluded due to resources constrains. It is acknowledged that some potentially relevant papers could have been missed due to this. The framework by Arskey and O'Malley recommends the sixth step of a stakeholder consultation to help identify additional relevant studies for inclusion and also provide feedback on the findings of the scoping review. Although this trip could provide potential valuable information, it was omitted in this study due to limited time resources.

The researcher intended to conduct primary research on families in the ICU. The research title was approved by the Postgraduate assessor panel and an ethics application was submitted.

Due to the COVID-19 pandemic and the national lockdown, visitation in the ICU by family members was prohibited. The researcher had to change to a literature review. This led to a lot of anxiety and uncertainty but this was fruitful exercise in the end. I learned a lot from this study.

5.5 RECOMMENDATIONS FOR FUTURE NURSING RESEARCH

The findings from this review suggest that family satisfaction with family involvement in decision making in ICU have not been investigated thoroughly within the critical care literature. Research gaps identified in this review suggest that extensive research is still needed to be conducted on the nature and extent of family involvement in decision making process in the intensive care unit. Future research is required also to investigate the factors that influence family involvement indecision making in the ICU including socio-cultural, organizational, contextual factors.

In terms of methodology, future research should consider triangulation of methods when investigating family satisfaction with family involvement in decision making in the ICU to improve and expand the findings. The future research might be strengthened by incorporating the ethnographic approaches that may produce in depth and context specific findings for family satisfaction with family involvement in decision making. In this scoping review, findings indicate that more studies have been done globally but in Africa there is lack of similar research. We recommend more research to be conducted in Sub- Saharan Africa focusing on family satisfaction with family involvement in decision making in ICU considering the unique racial, cultural, ethnic and linguistic differences found in African countries.

5.6 CONCLUSION

The scoping review of research studies from various countries set out to identify the extent and range of available literature research on family satisfaction with family involvement decision making in ICU.

The scoping review identified four categories of family satisfaction with family involvement in decision making in ICU topic that have been investigated in the intensive care research. This include: family satisfaction, communication and receiving information, inclusion in decision making and lastly support during decision making process.

The key finding that emerged from this scoping review is that family satisfaction with family involvement in decision making in ICU has not been thoroughly explored, most studies measured the family satisfaction level using FS-ICU tool which is limited in clarifying what actually happens in practice. It is clear from this review that there is evidence of gaps and inconsistencies in existing literature on family involvement in decision making in ICU therefore undertaking a full systematic review may be valuable.

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Appendix A

DATA COLLECTION TOOL

Data extraction tool	
Author (s)	
Year of publication	
Country	
Title of publication	
Aim/ objective	
Population/sample/sampling method	
Data collection/instrument	
Result / findings	
Implications/recommendations	

Appendix B
Ethical clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research & Post Graduate Affairs)

15/01/2021

Ref: W-CBP-210115-01

TO WHOM IT MAY CONCERN

Waiver: This certifies that the following research does not require clearance from the Human Research Ethics Committee (Medical)

Investigator: Ms O Baliki
Student No. (if appropriate): 0606434W
Staff No. (if appropriate):

Supervisor: Dr N Klaas

School: Therapeutic Sciences
Nursing Education
Medical School
University

Project title: *Family satisfaction with involvement of family members in decision making in the Intensive Care Unit: a scoping review*

Reason: Review of information in the public domain
No human participants will be involved in the study

Dr CB Penny
Chairperson: Human Research Ethics Committee (Medical)

Research Office Secretariat:
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Appendix C
Postgraduate Approval of Study

Private Bag 3 Wits, 2050
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UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

24 August 2021
Person No: 0606434W
TAA

Miss O Baliki
P O Box 30918
Metsef
Francistown
00
Botswana

Dear Miss Onalenna Baliki

Master of Science in Nursing: Change of title of research

I am pleased to inform you that the following change in the title of your Research Report for the degree of **Master of Science in Nursing** has been approved:

From:	**Family satisfaction with the quality of care of patients in the intensive care unit and involvement of family members in decision making**
To:	**Family satisfaction with involvement of family members in decision making in the intensive care unit: a scoping review**

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences