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### RESEARCH ARTICLE

#### LIVED EXPERIENCE OF PATIENTS UNDERGOING HEMODIALYSIS.

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#### Abstract

**Background:** Chronic kidney disease is a chronic illness, patients had to take long term treatment and depend on hemodialysis for their whole life. They suffer from physical problems, emotional problems and financial problems. **Objectives:** To understand the lived experience of patients undergoing hemodialysis. **Method:** The reviews were on the patients undergoing for hemodialysis by using phenomenological design and semi structured interview was done to collect the data from the patients. Data was coded by using thematic analysis were derived from them. Keyword searches of EBSCO, DELNET & Pub med-Medline databases, found 14 reviews selected 9 reviews for this study based on the lived experiences of patients undergoing hemodialysis. The 3 reviews are not based on the lived experiences of hemodialysis and in 2 review based on same article but there is no time duration of semi structured interview so those study were not included in the review. **Results:** Qualitative reviews (n=9) on lived experiences of patient undergoing hemodialysis. After analysing the results three themes has emerged out acceptance of illness, emotional distress and dependent on hemodialysis for living. **Conclusion:** Patients undergoing hemodialysis emerged out with lot of problems where they unaccepted the experiences and feeling of burden in society and thinks hemodialysis is a part of life due to lack of support and guidance From these reviews it helps nurses to utilize these information and guide patients to provide positive reinforcement for their future living.

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#### Introduction:-

Chronic kidney disease (CKD) is the worldwide health problem. According to World Health Organization Global burden of disease project, diseases of the kidney and urinary tract were contribute to global burden with approximately 850,000 deaths every year and 115,010,107 cause of disability. CKD is the 12<sup>th</sup> leading cause of death and 17<sup>th</sup> cause of disability.

In past, chronic glomerulonephritis was the most common cause of chronic renal failure, but today, diabetes mellitus and hypertension had taken center stage in the causation of ESRD which together account for almost 60% of hemodialysis patients with these causes.

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Patients with renal failure have been protectively treated in early stage of the disease and eventually they need a hemodialysis and renal transplantation for securing and extending their life. Hemodialysis is the most common protective treatment process in which the toxic nitrogenous substances, water and electrolytes are refined by hemodialysis unit in hemodialysis centers two or three times a week.

Patients with ESRD faced many challenges due to their disease condition which may leave them feeling fatigued and depressed (Theofilou, 2011, 2012). Their body image gets affected by fistula or grafting for dialysis access. Economically they get affected by the high cost of weekly treatments for hemodialysis and sometime admission to the emergency department due to the complications. Relationships and independency are also threatened (Karamanidou, Theofilou, Ginieri-Coccosis, Synodinou, & Papadimitriou, 2009; Theofilou, 2011).

Nurses and health professionals need to understand the lived experiences of patients on hemodialysis to respond to these physical, psychological, emotional, and spiritual changes. By gaining these insights, health professionals can develop appropriate nursing care and improve quality of care (Polaschek, 2003).

Thus, the purpose of this narrative review is to explore the lived experience of Chronic Kidney Disease and ESRD patients on routine hemodialysis treatments from their own perspectives.

## **Methods:-**

### **Search Strategy Methods**

An electronic search of articles published in various journals till January 2016 was conducted. Search was bounded to only English language. The database search done was Pub med- Medline, EBSCO and DELNET. Articles containing following key search terms were retrieved.

### **Types of studies:**

Qualitative studies with designs: Phenomenological designs, descriptive and exploratory design.

### **Type of participants:**

Patients undergoing hemodialysis more than one year.

### **Settings:**

Hospitals, health care centers.

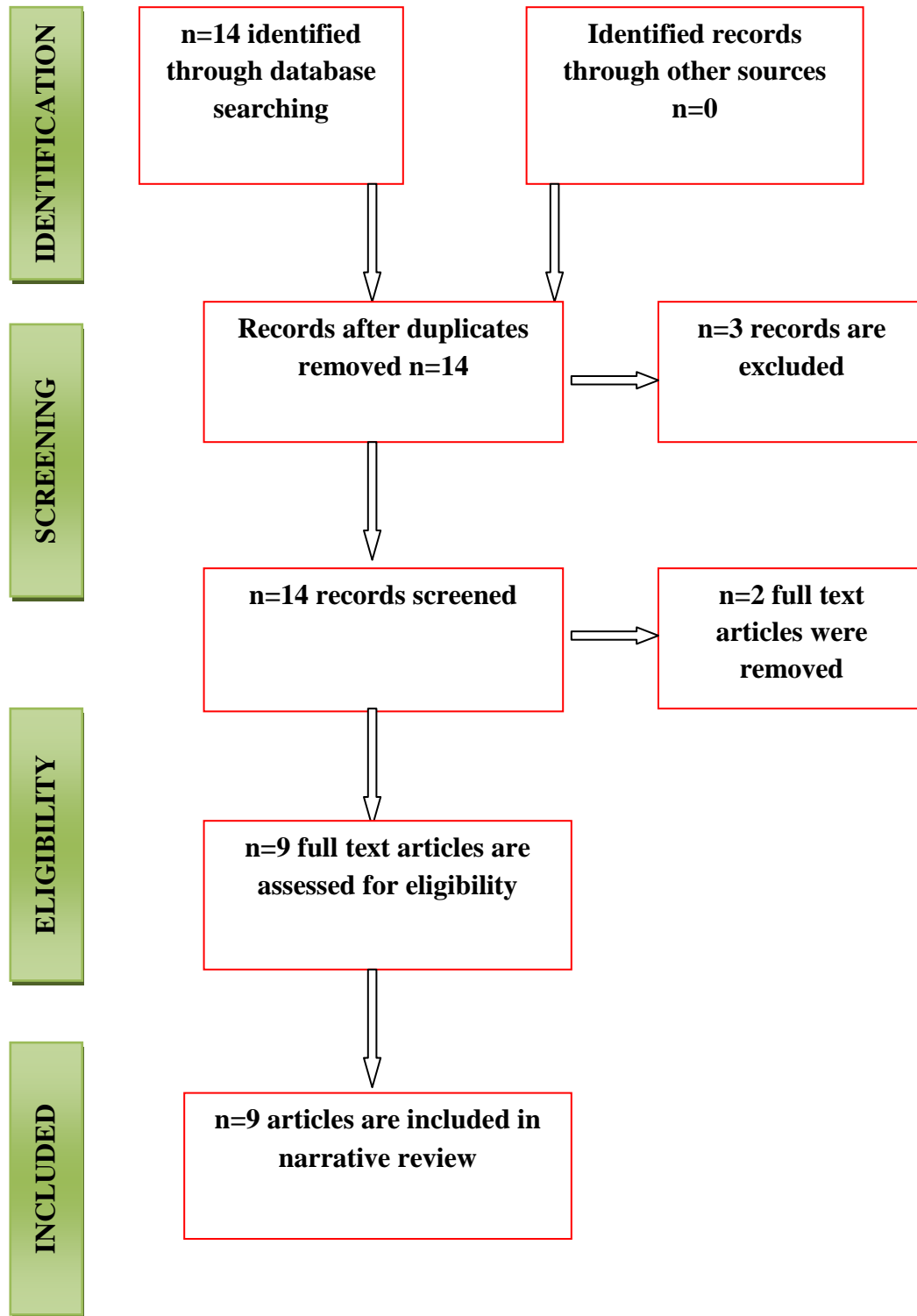


Figure 1:- PRISMA flow chart on narrative review.

**Result:-**

The review identifies two groups of qualitative studies on lived experiences of hemodialysis.

1. Studies that focused on lived experiences of patient undergoing hemodialysis (n=6, summarised in table 1) .First study focused on the acceptance of illness, second, third and fifth highlighted on the negative impact of illness in their live, fourth revealed emotional distress need of support, further study sixth focused on hemodialysis equal as life.
2. Studies differentiate between stress and life experience undergoing hemodialysis (n=3, summarised in table 2). First study conducted in India, Bangalore (2014) explored on the psychological emotional stress other two, one based that life without hemodialysis unaccepted conducted in Tehran (2010), other on sense of loss of life physically, mentally, socially.
3. After analysing the results three themes has emerged out **acceptance** of illness, **emotional distress** and **dependent** on hemodialysis for living.

**Acceptance:-**

In one review it reveals that patients have positive outlook towards the hemodialysis as patients psychologically and mentally changed they manage in the dietary habits and life style and accepted the changes in their ongoing treatment of hemodialysis.

*“I like coming to treatments and leaving here feeling better than I did before... Dialysis is definitely a good thing for me.”*

*“I have learn not to drink lot of salty stuffs, and not to eat more stuff that damage the body, and I learned how to take care of myself.”*

**Emotional Distress:-**

Mostly patient suffering from the illness feeling of isolation from society, burden for family members, feeling neglected , physical limitations, fatigue not able to perform daily activities, unemployment and lot of challenges faced during the illness and difficult to survive with the severe problems facing due to hemodialysis ongoing treatment .

*“I feel, as if I am dead, my mind is not there with me, no interest to live... I can no longer feel or enjoy anything.”*

*“Neighbors and relatives stopped talking to us ; they are scared that we may ask for money from them.”*

*“I cannot lie down or sleep due to severe breathlessness and not able to perform my daily activities due to fear of fistula”.*

**Dependent:-** In some reviews patients undergoing hemodialysis feels that life without hemodialysis is lifeless they depend on hemodialysis for their living which bring hope of living, feels hemodialysis is a part of their life for surviving.

*“This is our life, all of it is dialysis, if we don't come here for one day it is not clear what will happen to us, surely we die, it is more important than our women and children”.*

**Table 1:-** Summary of study characteristics: lived experience patient undergoing hemodialysis

S.NO.	PROBLEM STATEMENT/AUTHOR	PLACE OF RESEARCH & YEAR	RESEARCH OBJECTIVE	VARIABLES	TOOLS	TIME DURATION	OUTCOMES	REMARK
1.	A qualitative study on- What Is The Lived Experience Of The Client With End Stage Renal Disease On Hemodialysis.  Diane Scaife	United States midwestern, 2006	To understand the lived experience of the client with end stage renal disease on hemodialysis.	Lived experience of the client	Semi structured interview	30 to 40 min.	The outcome of this study is acceptance of illness in them.	The sample size is too small. Other that in this study it only include the patient with end stage renal disease
2.	A Qualitative Research on the Experience of Hemodialysis in South Karnataka: Lived Experience of Persons undergoing Hemodialysis  Blessy Prabha Valsaraj, Shripathy M Bhatt, Ravindra Prabhu, Dinesh N.	Kasturba Hospital South Karnataka , December 2011 to December 2012	To explore the lived experiences of person undergoing hemodialysis.	Lived experience of persons undergoing hemodialysis.	Semi structured interview	50 to 60 minutes	In this study it revealed that person is having negativity towards their illness and treatment .	In this study researcher unable to understand and respondents and done the interview two times.
3.	Undergoing Hemodialysis: A Qualitative Study to Investigate the Lived Experiences of Patients  Paraskevi Theofilou,	Greece , 2009	To investigate the lived experiences of hemodialysis patients.	Lived experiences of patients undergoing hemodialysis	Semi structured interview	50 minutes	In this study it revealed that patients have negative impact in their social health	In this study not define sampling technique, the exclusion criteria

	Clairy Synodinoua, Helen Panagiotakic						and daily lives.	and at what duration they have collected the data.
4.	Starting on hemodialysis: A qualitative study to explore the experience and needs of incident patients  Alden Yuanhong Lai, Angela Ping Ping Loh, Nandakumar Mooppil, Deby Sarojiyu Pala Krishnan and Konstadina Griva	Singapore , 2011	To explore the lived experience of hemodialysis patient.	Experience and need of patients.	Semi structured interview	35 to 50 minutes	In this study it revealed the patients is having more emotional distress after knowing about illness and need of information and knowledge regarding illness.	In this study it discusses the participants with diabetes and central venous catheter but in study it not mentions the statistics problem with this condition.
5.	Lived Experience of Patients Undergoing Hemodialysis: Quality of Life Perspective  Mrs. Rohini. , Dr. Punitha. V. Ezhilarasu	Ernakulam district in Kerala , 2014	To explore the lived experience of quality of life among patients undergoing hemodialysis.	Lived experience of patients undergoing hemodialysis	Semi structured interview	15-20 minutes	In this study it revealed the negative experience towards their illness and need of knowledge regarding their treatment and illness.	Inclusion criteria are not mentioned and also age limitation is not present in this study.
6.	The Lived Experience of Patients' with End Stage Renal Disease	Ministry of Health hospitals, 2014	To describe the lived experiences of patients with end	Lived experiences of patients with	In depth semi structured interview	60 min.	In this study it reveals that with hemodial	In this study it not mention at

on Hemodialysis: A Phenomenological Study	Dr. Suhair Al-Ghabeesh, Dr. Khaled Suleiman	stage renal disease on hemodialysis treatment.	ESRD	w		ysis is part which equitable to their lives.	which duration the researcher collected the data.
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**Table 2:-** Summary of Study Characteristics Differentiate Between Stress and Life Undergoing Hemodialysis

S.NO	PROBLEM STATEMENT/AUTHOR	PLACE OF RESEARCH & YEAR	OBJECTIVES	RESEARCH VARIABLE	TOOLS	TIME DURATION	OUTCOMES	REMARK
1.	Understanding the experience of stress on initiation of hemodialysis :A phenomenological study  Sonali Tarachand Jadhav, Premila Lee	Two private hospitals in Bangalore , India, 2014	To identify the stressors experienced by the patient with CKD undergoing hemodialysis.	Experience of stress on initiation of hemodialysis	Semi structured interview	30 to 60 minutes	In this study it revealed that most of the adult's patients suffered from the psychological and socioeconomic stress.	A study should include the patient with uremia, hyperkalemia undergoing hemodialysis. Other it can take the patient experience more than a year rather than 6 year.
2.	Life with hemodialysis unit: A phenomenological study  Fateme Pashaii Sabet, Alireza Nikbakht Nasrabadi , Nahid Karami Kabir	Ekbatan University Hospital of Hamedan and Shohadaye Yaft Abad Hospital of Tehran, 2010	To understand better about patients life with hemodialysis unit	Life with hemodialysis unit.	In depth and semi structured interviews	40 to 60 minutes	In this study it reveals that life without hemodialysis is impossible to survive.	In this study it did not explain when they have collected data from patient in unit or after dialysis.

3.	A 'lost life': coming to terms with hemodialysis  Susan Monaro, Glenn Stewart and Janice Gullick	Sydney , 2008-2010	To describe the essence of the lived experiences of patients and families in the early phase of long term hemodialysis therapy.	Lived experiences of patients and family	Semi structure interview	26-72 min.	In this study it revealed that sense of loss they perceive from socially, mentally or physically lost all the pleasure happiness due to their illness.	In this study in most of the participants both families and patient were not interviewed. They take interview of patient or either family or also no exclusion criteria are given.
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### Discussion:-

The qualitative studies of patients undergoing hemodialysis , mostly the research has been conducted in foreign countries: United States of America, Greece, Taiwan, Saudi Arabia and in India one study conducted in south Karnataka kasturba hospital.

This article observed that various themes emerged out acceptance, emotional distress and dependent. Some patients had a positive outlook towards it, others feel that hemodialysis psychologically and socially disturbed and which adhere their daily living and also suffer from deep pain, and others thought hemodialysis is the part of daily living for survival.

One study compared conducted this meta-synthesis analyzed and synthesized findings from qualitative studies of lived experiences of patients on hemodialysis. Four themes emerged as a result of synthesizing findings of the studies: having a physical shackle in life, feeling mental and emotional distress, relying on a hemodialysis machine, and dealing with problems. The themes of having a physical shackle in life and mental and emotional distress have a strong relationship.

### Implications:-

Patients on hemodialysis have many difficulties and sufferings due to their illness and hemodialysis therapy. Individual and social aspects of their life, as well as physical and mental emotional problems, should be considered and understood by nurses and significant others. These problems should be solved so patients may achieve optimum health status and the balance of physical and psychological aspects of their overall life as well as individual and social life and to develop positivity towards their lives.

More studies should be conduct on lived experiences in India to understand more insights and to explore their sufferings which helps much more for health professionals to educate them regarding illness and reduce negative aspects of living.

### Conclusion:-

The review makes an important contribution to understand the lived experiences of patients undergoing for hemodialysis and its describes in the patients perspectives that Patients on hemodialysis have some positivity, difficulties and sufferings due to their illness and hemodialysis therapy.



These problems should be solved so patients may achieve optimum health status and the balance of physical and psychological aspects of their overall life as well as individual and social life and to develop positivity towards their lives.

In future more studies should be conducted on lived experiences of patients undergoing hemodialysis to understand their insights and to explore their sufferings which helps much more for health professionals to educate them regarding illness and reduce the negative aspects of living.

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