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A study to explore lived experiences of patients receiving hemodialysis at selected referral hospitals of Jabalpur city, with developing an intervention and identify health needs to improve health services

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Abstract

Hemodialysis is an obligatory boon cum life-long aftermath for patients with compromised kidney performance.

Aim: The aim of study was to explore lived experiences of patients receiving hemodialysis at selected referral hospitals of Jabalpur city, with developing an intervention and identify health needs to improve health services.

Objectives

1. To explore lived experiences of patients receiving hemodialysis.
2. To identify the health needs of patients receiving hemodialysis.
3. To develop an intervention.

Methodology: 100 patients, receiving hemodialysis were selected from hemodialysis unit of Medical College Jabalpur, using non- probability convenient sampling.

Results: Seven distinct major themes developed-Coping and new self, Plethora of manifestations, financial breakdown, future insecurities, struggle versus hope for survival, feeling of dependency and lack of awareness.

Keywords: Hemodialysis, lived experiences, health needs

Introduction

Hemodialysis is an obligatory boon cum life-long aftermath for patients with compromised kidney performance. Their life experiences might be a mirror to their health needs and prompts to care planning to improve quality of life.

Need for the study: One in ten adults get hit by chronic kidney disease (CKD). The global burden of CKD is expanding, and by 2040 it is forecasted to become the 5th most common cause of years of life lost globally. Chronic kidney disease contributes to a major proportion of catastrophic health expenditure in both developed and developing economies. The purpose of this study is to have an insight to the changes in every aspect of life of this population, after initiation of hemodialysis, and also identify their health needs. Perhaps stepping into the lives of patients and empathize with their subjective experiences within the hemodialysis units, might give rise to common themes that might support a sustainable intervention and be the foundation to implement social change.

Researcher aims at evaluating health needs and subjective experience of hemodialysis patients within the facility, giving rise to common themes that might support a sustainable intervention and be foundation to implement the desired change.

Statement of the problem: A study to explore lived experiences of patients receiving hemodialysis at selected referral hospitals of Jabalpur city, with developing an intervention and identify health needs to improve health services.

Objectives

1. To explore lived experiences of patients receiving hemodialysis.

- To identify the health needs of patients receiving hemodialysis.
- To develop an intervention

Methodology

Research approach: A qualitative phenomenological approach was adapted to enrich the inquiry of the area under the study.

Research design: A phenomenological approach was adapted to enrich the inquiry of the area under the study.

Setting of the study: Study was conducted in Medical College Hospital Jabalpur.

Target Population:

In this study the target population consists of patients receiving hemodialysis.

Accessible population:

Accessible Population consists of the patient receiving hemodialysis in selected referral hospitals of Jabalpur City.

Sample selecting criteria

The inclusion criteria set for the selection of the subjects are:

Inclusion Criteria

- Hemodialysis patients providing consent to participate in the study
- Being registered in the hemodialysis unit of selected

referral hospitals

- Only adults patients receiving hemodialysis
- Patients receiving hemodialysis since more than 3 months

Exclusion Criteria

- Lack of volunteering to participate in the study.
- Unconscious patients
- Suffering from mental and cognitive diseases.

Research Variables: Lived experiences and health needs of the patients are the two research variables to be investigated in this study, followed by development of an intervention.

Demographic variables: Demographic variables include age, gender, education, marital status, occupation, religion, residence, type of family, habit and clinical profile.

Description of tools

Researcher aims to collect data, by the means of 3 types of tools. First one was Structured questionnaire and record analysis on background information. Another tool included Semi-structured interview guide on lived experience of patient receiving hemodialysis and third tools was a unstructured questionnaire to identify the health needs of patients.

Data analysis and Discussion

Seven major themes were extracted from the data obtained by interview.

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S. No	Themes	Subthemes	N	%
1	Coping and new self	Challenges of haemodialysis, Cluster of restrictions	96	96%
2	Plethora of manifestations	Unending physical discomfort, psychological impact	100	100%
3	Financial breakdown	Travelling cost, rent, attendant's expenses	82	82%
4	Future insecurities	Seriousness of the disease, Family concerns and support, Almighty is last hope	100	100%
5	Struggle versus hope for survival	Struggling for survival, adjusting with odds to live with loved ones	78	78%
6	Feeling of dependency	Guilt feeling, helplessness	76	76%
7	Lack of awareness	Information deficit, no idea of disease prognosis	50	50%

Major findings of the study

After analysis of voluminous qualitative data regarding researcher identified seven distinct major themes-Coping and new self, Plethora of manifestations, financial breakdown, future insecurities, struggle versus hope for survival, feeling of dependency and lack of awareness.

Analysis of data collected to explore health needs of patients undergoing hemodialysis, resulted in multiple subthemes categorized under five major themes to describe the health needs. These themes include, need for freedom from physical and emotional repercussions, need for love and respect and spirituality, need for Comprehensive care and independence, need for Support and empowerment, and need for information and communication.

Recommendations: Study recommends to stakeholders, policy makers, managers, and program to ensure construction of care and any possible intervention in the light of explored experiences and felt needs of population subjected through the hemodialysis, to ensure the utmost satisfaction and perfection in terms of quality, benefits and holistic care provision.

Conclusion

Tiresome physical and mental agony, a bundle of hidden feelings and heavy burden of responsibilities exposes hemodialysis patients to vulnerability. As a result of government efforts, though hemodialysis patients are getting best possible free of cost care in dialysis unit, still they feel to share their existential thoughts to be voiced. It is need of the hour to plan patient centred care guided by their felt experiences to address their overlooked needs in all the domains. It would be a noble effort to make them live smoothly with least discomfort and more of satisfaction to the health care services.

Conflict of Interest

Not available

Financial Support

Not available

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