

Quality of Life in Maintenance Hemodialysis; Stakeholders' Perspectives – A Qualitative Inquiry

Radhika C K¹, Asha S Kumar²

¹Assistant Professor, Govt. College of Nursing, Thiruvananthapuram,

²Principal, SIMET College of Nursing, Thiruvananthapuram

Abstract

Quality of life is a major concept in the arena of healthcare, especially in chronic diseases. ESRD patients undergoing maintenance hemodialysis experience unique issues involving varying aspects. Using a qualitative approach, the current study explored the perspectives of stakeholders on quality of life. Thematic analysis done and three major themes - Dialysis - the life line, Global impact of the disease and strategies to be made, were emerged. Quality of life in hemodialysis patients is markedly impaired due to a variety of factors and a comprehensive and tailored approach will be beneficial.

Keywords: Hemodialysis, Quality of Life, Qualitative, Kerala)

Introduction

Chronic diseases carry a distressing concern among all stakeholders of the health care delivery system. Quality of life, one of the most important health related indicator facilitates important information regarding patients' perceptions of their life. Maintenance hemodialysis population experience many constraints in day to day life and these will possess a substantial bearing on their quality of life¹. According to the World Health Organization (WHO), quality of life is "a broad ranging concept affected by the person's complex physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment"².

Maintenance hemodialysis is a major treatment option in ESRD though kidney transplantation is considered as a more preferable renal replacement alternative in terms of quality of life. But the cost involved and dearth of donors makes it a less popular option and this forces the patients to continue on maintenance hemodialysis (MHD) for sustaining their life especially in middle and low income countries like India³. Though there are plethora of numerical tools to measure the health related quality of life in dialysis, use of an optimal tool is always controversial⁴. Here the researchers assumed that a qualitative approach will throw much light into the nuances of their perceptions and outlook towards life. So this study aimed to explore the QOL of patients with ESRD on maintenance hemodialysis through various stakeholders.

Materials and Methods

A qualitative thematic approach was used to explore the topic under study. Study setting was the dialysis unit of a tertiary care center from South Kerala, India. A non-probabilistic purposive sampling was used to select appropriate participants so as to

Corresponding author:

Radhika C K,

Assistant Professor, Govt. College of Nursing,
Thiruvananthapuram.

mail id: radhikasreedhar1999@gmail.com)

generate rich data on the attribute. The major mode of data collection was in-depth interviews (among 6 patients, 4 family members, 2 nurses, 2 doctors and one dialysis technician) and FGDs (2), conducted based on an interview guide grounded in study objectives (Table 1). Data collection took place at a mutually agreed time, which stretched a period of seven months and each session lasts around 45- 60 minutes. The whole process of communication was

audio recorded with permission. Serial field notes also were taken generously to have a rich description of the data.

Institutional ethics committee approval obtained prior to the conduct of the study and written informed consent from the patients and family members also collected. The whole study process adhered to the ethical principles of health research.

Table: 1 population characteristics

S No.	Characteristics	Value (n =15)
Respondents - Patients		n = 6
1.	Mean age	60 (± 9.4), Range 43-76
2.	Gender (Male / Female)	5 / 3
3.	Mean years of dialysis	4.57 (± 1.74)
Respondents - Family members		n = 4
4.	Mean age	46 yrs.
5.	Gender (Male / Female)	2 / 3
6.	Relationship with the patients	Spouse
Respondents – Health care personnel		n = 5
7.	Nurses	2
8.	Nephrologist	2
9.	Dialysis Technician	1
10.	Mean Years of experience	7 (± 3.39) Range 3 – 11 yrs.

Data analysis has been viewed as the most complex and enigmatic phase in qualitative research⁵. Here the researcher carried out a thematic analysis by following the linear six step process postulated by Braun and

Clarke ⁶. At first, the researcher reviewed the field notes, listened to the audio clips, made transcripts and then read and re-read the transcripts to catch promising codes. Preliminary codes were identified

and in the second phase, scrutinized these in a view to develop subthemes. In the third phase, researchers picked out the quotes which are in agreement with the central themes. Then the themes were reviewed and later defined and named them. As the themes get finalized, report writing process started.

Results

The data analysis produced three themes. *Dialysis - the life line, Global impact of the disease and strategies to be made.*

Theme 1 Dialysis - the life line

Though there are innumerable distresses and concerns associated with dialysis, people view it as a grip to life too. As one elderly male patient commented,

“Without this, how could I have survived? At least a facility is there to avail... I think I should be grateful to this.....” (69 yr. old female patient on MHD for 5 yrs.)

“I am little tired after dialysis...but after some time I will be ok. Happily living with wife, children and grandchildren.... so dialysis... in fact keeps me forward...”

(72 yr. old male patient on MHD for 6 yrs.)

Theme 2 Global impact of the disease

Participants described their disease experiences as something which covers almost all domains of life such as physical, psychological and social.

Physical issues

Most of the patients reported an array of physical symptoms which in fact limit their life in many ways. Among them, the most reverberated issue was sleep disturbances. Though it is listed under the subtheme physical issues, its psychological underpinnings cannot be denied.

“I couldn't sleep..... Sleepless nights ...quite common now..... you know...now, my earnest desire is to sleep madly.... fed up with this long night hours... simply lying in bed... same thing every day and every night.” (67 yr. old male patient on MHD for 6 yrs.)

Apart from sleep, most frequently quoted difficulties were dyspnea, anorexia, pain and generalized skin issues like itching or irritability.

“For years...I have been sleeping in sitting position...breathlessness is always there.”

(68 yr. old female patient)

Anorexia was not reported as a rampant issue, but still, few expressed it as something always annoying...

“I used to think and plan to eat something to get rid of fatigue... but no taste at all...don't like food nowadays.....very little only I eat”. (56 yr. old female patient)

“Itchy feel is terrible..... Irresistible.”. (72 yr. old male patient)

Ø Psycho social issues

Frustration and despair out of restrictions (mostly dietary) were some common reflections from patients.

“Its no..... no....everywhere.....my wildest thought is to drink enough water without any limit..... may be next birth.... (smiles wryly) (Male patient, 69 yrs. MHD for last 4 yrs.)

Existing burden of a chronic illness get augmented many times with the frequent hospitalizations. An array of negative emotions also expressed mostly by the family members regarding the patient's behavior. Though it was not obvious during the interview, at times it gets reflected.

“Very difficult to manage his behavior. Previously also he was very short-tempered. Now with these disturbances, it gets worsened. just added up the

troubles..... Now all the time he is extremely arrogant and irritable even for silly matters. To tell you the truth..... I am really fed up.....” (Spouse, Female, 59 yrs.)

“Still he wanted to look after all family affairs. But the thing is that..... he is not able to. But he never admits that..... sometimes I feel my head is shattered.... you know he speaks like that...” (Wife, Female, 44 yrs.)

Similar kind of overt or covert signs of straining relations could observe during interactions. Certain patients were reluctant to open up their issues with the family. One lady who is a widow and stays with the daughter revealed,

“I used to have extreme lethargy....at times...but I won't tell her. (Patient, Female, 68 yrs.)

‘Being dependent, was a major disappointing concern expressed by majority of the patients across gender or other demographic factors. ‘Distress out of dependency role’.

“I was the senior most person in our family...an elder brother figure...I used to run for all... but now, what happened? I am bound to this machine.... here they (nurses) decide my routine. Everybody used to care me a lot. But I feel very much belittled...” (Patient, Male, 68 yrs.)

Annoyance and irritability out of surroundings especially the familial and social surroundings were also evident in the talk.

“The funny thing is that every people around me are advisors.....kuzhappamilla.... ellam sheriyakum’ is the most dreaded statement for me nowadays..... simply showing sympathy and hollow words...no use at all....” (Patient, Male, 57 yrs.)

Though not so predominant, many times negative or depressive shades were evolved out of interactions.

“For me, now life means something always

going through the same route...same people around... weather in hospital or home. You know..... how this disease turned my life upside down?” (32 yr. old male patient – CKDu, on MHD for 2 yrs.)

Some of the participants especially, patients with CKD of unknown origin often expressed their disbelief over this machine dependent life. A young Male patient, 32yrs. commented,

I was a person surrounded by friends. Now everything around this machine. Suicide is not an option...right? (smiles wryly) Just going with the flow.....that's all.

Perceived state of extreme alienation and fear of death

A gradual yet, painful process of moving back from the habitual, relentless interactions with the society and stepping in a circumscribed, limited circle was a major concern expressed by many.

“You know... I was always around people... at my shop.....that was my routine...once.....(sighs...) off dialysis days I used to be there.....even now.... but I think people view me differently.....a disease role!!

One of the major concern expressed by many are the feeling of a mechanized life. Two participants have used the term ‘tied to a machine’. A 59 yr. old male retired government official who previously enjoyed an active community living commented,

“No social life, functions...outing.... something like tied.....totally stagnant life...”

More or less negative tones were the most predominant feelings throughout...The whole flood of feelings swings around anger, grief, annoyance, distress and so on.... Certain participants also expressed their agony over rejection or neglect by the friends and kinfolks.

“You know...it's a new period in life.....what to say? The whole routine turns to a new set of things....

hospital may be..... my second home...every other day I have to be here..... what to do? This is fate...I didn't even think of such a twist in my life.....if you are being excluding from known circles.....means....it is the most hurting thing.” (CKDu, Patient, Male, 32 yrs.)

Our son is staying nearby only.....he could pay occasional visits.... but he never does.....a burden may be.....” (spouse, female, 62 yrs.)

Concerns regarding death, though preferred to be masked often overflowed during sessions. The unexpected, abrupt nature of death among dialysis patients made them more nervous and worried.

Actually speaking.....now my best company is here only.....kind of relatives.....regularly meeting them.....we know each other...sharing the sorrows and joys together.... the most troubling thing...you know.....all of a sudden we hear...he is no more...one fine morning.... that's horrible.....a creepy feel it's..... of imminent death.....who knows..... who's next?

(Patient, Male, 58 yrs.)

Theme 3 Strategies to be made

Individualized and more organized style of care are imperative in dialysis care as highlighted by the healthcare team we interviewed. Major subthemes evolved were holistic person centered care and need of comprehensive ongoing patient support services.

Holistic person centered approach

Remarks from the health care providers implied that the measures which they adopt need a sea change. Many thoughts have evolved over the talks such as, hectic schedules, lack of a genuine effort to integrate newer concepts in care and dearth of an ongoing wholesome patient support system. A practicing nephrologist commented,

“It is totally unacceptable that.....we do not have a clinical practice guideline of our own. As some are in pipeline, lets expect the same in near future.

“(Nephrologist, 48 yr. old, Male)

Change in the pattern of management before and after dialysis has been highlighted by practitioners. Lack of a comprehensive preparation and orientation were also mentioned.

“A preemptive channel for hemodialysis is very much important.... that will equip these patients to better adapt to the challenges imposed of a new life”.

“Therapeutic communication is the most important thing. In fact, lending an ear to patients is a great thing. But the hectic schedules.... often may be task oriented.....need to restructure and modify this”. (Nurse in charge, Female, 46 yrs.)

“A ‘one size fits all’ approach is not at all suitable.... have to have tailored, sufficient and continuous opportunity for interactions with the patient and family.....ya...quality time”. (Nephrology resident, female, 32 yrs.)

“I think one major issue in communication is due to the lack of consistency of the care giver”. (Nephrology resident, Female, 32 yrs.)

And you know...it's something mechanical..... they are always concerned about schedules..... and we.... getting sessions done... and wrapping up. So I think...have to go more and find time to speak with them.....apart from the usual hai..... bye..., and routine procedures like weighing or BP monitoring, (Dialysis technician, Female, 29 yrs.)

Comprehensive patient support services

Majority of the patients and family were yet curious, but not aware about the basic physiologic alterations with CKD and dialysis.

They are in fact.... not aware about the underlying pathological changes and the therapeutic measures which the new situation demand.....yes...definitely..... we have to train them a lot....” (Nephrologist, Male,

48yrs.)

Majority of the participants made positive comments about the health related information they received from their health providers and proposed few suggestions also for spreading awareness on related field.

“I pay regular visit to doctor and follows the prescriptions....and you know...always he finds time to clear my doubts”. But to be frank...I am very much hesitated to ask many of my queries”. (Patient, Male, 57 yrs.)

“I told you know.... I used to dump a bagful of doubts here.... they (sisters) will answer.... so kind they all are(smiles)but busy too.... I always think and tell them that if it is possible to have someone there for us.....to listen...and to clear up our worries.....fears... and concerns....it could have been a great relief for the patients and relatives.” (Patient, Female, 48 yrs.)

Discussion

In this qualitative study, we aimed to explore the various aspects of quality of life of dialysis patients through different stakeholders. This study finding revealed that a majority of participants with ESRD on dialysis were experiencing varying degrees of stresses. Ranging from physical to emotional and social, this population experience incomparable distresses out of disease and treatment modality as well. This is in congruence with few previous studies⁷.

Family members also going through marked emotional burden which is an established finding across many studies⁸. Family play a crucial role in the care of dialysis patients. But whether they receive sufficient acknowledgement and support is questionable⁹.

Few patients, especially, elderly find dialysis as a bridge to life itself. This can be viewed as a thought of positive coping and spiritual enlightenment. Among the literature, very few studies only have reported

these sort of a positive stroke¹⁰.

Though there are limited social security measures available in Kerala, hemodialysis patient related services requires structural changes in many aspects. health care personnel participated in the study also expressed the same¹¹.

This study has conducted at one of the premier tertiary care hospital of south India in public sector. So the researcher could handpick representative subjects from various strata of society.

Conclusion

Striking deterioration in the quality of life of dialysis patients deserves ongoing evaluation and demands center specific, tailored interventions. The findings of this study propose a patient centered team approach in enhancing the quality of life and assuring a dignified life for the dialysis population.

Conflicts of interest

Both authors Radhika C K & Dr. Asha S Kumar have nothing to disclose and declare that they have no conflict of interest.

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Ethical Clearance: All procedures followed were in accordance with the ethical standards laid down by the international, national and institutional bodies. Informed consent was obtained from all patients for being included in the study.

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