BASELINE QUALITY OF LIFE AMONG PATIENTS WITH END STAGE KIDNEY DISEASE IN A RESOURCE LIMITED SETTING

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Background

At 23% the prevalence of chronic kidney disease in sub-Saharan Africa is higher than the global prevalence of 16%. With no national healthcare coverage for hemodialysis or kidney transplant, Ugandan patients struggle to pay driving communities into poverty. Studies in developed countries show that patients on hemodialysis may prioritize quality of life (QoL) over survival time. There is a dearth of information about QoL of patients with End Stage Kidney Disease (ESKD) in LMIC.

Aim

Establish a baseline review of QoL, patient outcomes and associated factors for patients with ESKD receiving hemodialysis versus conservative management in a national referral hospital.

Methods

A mixed methods analytical study using the Kidney Disease Quality of Life Short Form, African APCA POS and Renal POS. Clinical, demographic and micro-financial information was collected and patient experiences explored using semi-structured interviews.

Results

38 patients completed with 6 interviewed. 32(84%) were on hemodialysis and 6 on conservative management. Patients aged from 19 to 78 years with 47% under 50 years. 68% were males, 52% had >3 dependants, while 37% were breadwinners. Majority(81%) were receiving twice weekly dialysis. On assessment of QoL: 91% felt kidney disease interfered too much with their life. 37% felt they were a burden to their family, 61% felt very frustrated with their lives. Average pain score (POS) was 2.4 with 27% reporting severe or overwhelming pain. Most had only 1 additional symptom with breathlessness highest prevalence (16%). Extensive co-morbidities present; 90% hypertension & 50% diabetes

Key themes

Financial constraints 'I wish God could take me before I deplete my family's resources' ,

"The Doctor told us that every day has to get an injection and in a week there is that injection he has to get injected the one they inject on the arm ,that medicine costs sixty thousand Ugandan shillings(60,000/-) and the other I buy nineteen thousand Ugandan shillings(19,000/-) when you add on the tablets they do prescribe for him making approximately a total of one hundred thirty thousand Ugandan shillings(130,000/-) every week. Now a farmer like me honestly where can I get that money?"

Disease burden and comorbidities, strong social support systems: "I was working but again I have been down for 2 years so they have been supporting me they are the ones taking care of me I have kids they are the ones taking care of my kids"

"Importance of spirituality: "for me I always keep myself to God so I said let God give the doctors strengthen power to cure this disease",

Loss of hope and feelings of helplessness:

"that is exactly what makes me feel very bad. You keep begging for everything and this makes life difficult especially if you used to work and now you are unemployed"

"I don't know but if that is the only alternative its better they leave me alone and I stay coming here. Keep coming on and off until such a time when you will die that is what is left for me"

Figure 1: GENERAL HEALTH PERCEPTION

Conclusions

Improved QoL is a key indicator of successful chronic disease management. This baseline review will inform a wider mixed methods longitudinal study. Improving this evidence base will inform renal and palliative care services with the aim of improving patient experience.