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Original Research Paper

Arts

PREVENTION OF CHRONIC KIDNEY DISEASE THROUGH FOCUSSED GROUP DISCUSSION

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ABSTRACT Prevention programs will function best when they operate as part of a national non-communicable disease strategy, with more involvement of being recommended strongly, post the beneficial outcomes of prevention interventions and suggest that a targeted self-management program can improve patient self-management and patient centered outcomes. Focus group discussions is a form of qualitative research method in which the interviewer (also called the moderator) asks research participants specific questions about a topic or an issue in a group discussion.

KEYWORDS :

INTRODUCTION

Chronic kidney disease (CKD) is prevalent worldwide and is ranked as one of the top ten chronic illnesses. CKD is defined as kidney damage occurring as proteinuria, hematuria, or an anatomical abnormality. Living with kidney disease usually requires changes in the person's lifestyle, especially in the early stage of CKD (Eknoyan G,2013).

Focus groups, unlike individual interviews, provide the added dimension of the interactions among members. Instead of the moderator asking questions, the group members are encouraged to communicate with one another, exchanging ideas and comments on each other experiences or points to view (Kitzinger.J, 1994).

MEHTODOLOGY

The aim of this paper is to evaluate a personal health practices as CKD patients and strengthening patients' participation in their health care process. Conducting a focus group requires high level of resources. The process involves formulating research questions, developing protocols, soliciting participants, arranging venues, facilitating focus groups, transcribing, setting of norms like Do's and Don'ts and reporting the findings. Semi-structured discussion guides were used, and the groups were video- and audio recorded. The interviews lasted approximately 1 hour, and the interview questions were guided by the chronological order in which the focus group is organized and conducted (recruitment, preparation, moderation, methods) and by the utilization and usefulness of the results.

Problem Identification

- Patients of CKD were observed to be more depressed and feel stressed due to the fear of death
- Lack of Proper Self care management of the respondents
- Poor access to health care services
- Increased Social Support system

Programme Planning

The moderator of FGD is to enable members to plan sessions by observing, listening and acting, visiting, consulting, analyzing and recording the process of discussion among the group. The moderator will be in program activities and leading the group in such a way that the members enjoy participation and opportunities for involvement are created even among the less dominant ones. The moderator planned the group discussions in the Nephrology ward of the RIMS in Srikakulam around 7-8 p.m as it is the time for their leisure and to avoid disturbances from the staff.

Recruitment Of The Group

The researcher (Moderator) recruited adult patients aged 20 to 65 years with CKD stages 3 and 4 who were currently physically active in Nephrologyclinic at the Rajiv Gandhi Institute of Medical sciences in Srikakaulam district of Andhra Pradesh. The respondents were purposively sampled based on age, sex, religion, and kidney function to ensure a diverse range of demographic and clinical characteristics. Focus groups were formed by sex and language (Telugu). Groups were formed with same clinical characteristics because they have different views and may not feel comfortable discussing issues regarding their problems as CKD patients.

Group Composition

Group members in focus group restricted to homogeneous along common dimensions and problems regard to chronic kidney diseases. The decision is also largely determined by the purpose of the research. This is particularly evident in the discussions about sensitive issues, such as factors associated with CKD, the sharing of experience, and the sense of "everyone in the same boat" is particularly significant to facilitate disclosure.

Setting

The moderator has planned to provide focus group session, it is very important to give care consideration of physical setting. With the oral permission of the Head of Nephrology ward, the moderator intimated the patients about the venue (Seminar hall) which is comfortable and conducive to discussion and also to avoid noises and distractions from external environment. On the other hand, selected focus group site is also geographically convenient for the participants to avoid confusion and time management for the group discussion. Moderator arranged their seats around the table which make them to enable to see and hear each other.

ACTIVITIES

Besides providing environment for discussion, the researcher induced behavioral changes or attitudinal changes among the participants through the plat-form of discussion. Keeping a record of discussion has been useful. Organizing discussions includes achievement of objectives, level of awareness on CKD among the members, psycho social problems including self care management after the diagnosis. The discussion was carefully lead by the moderator to generate discussion and in-depth information about the problems. The FGD is used as a medium to help them reflect rather than follow instructions without understanding. The group members set the norms and conditions before starting the discussion. Hence, the focused group discussion has been organized with the homogenous group of members suffering with CKD problems.

Session – I

A point that was strongly emphasized by the interviewees was the duration of the round of introductions at the beginning of the focus group session. In the patient groups, introductions took much more time than the researchers had expected. Patients had a high need to express themselves and to tell the others about their illness and their experiences with the health system. Although this left less time to work through the other issues, the researcher came to realize that there were several good reasons not to limit these contributions: First, the introductions round proved important for helping the participants to "arrive" at the focus group, for creating a basis of trust, and for building up a sense of community among the participants. Second, the interviewees reported that, because many issues (e.g., participants' experiences with the CKD, psychological problems and etc) had already been brought up in the round of introductions,

Psychological Problems

All the group members were introduced among themselves. After the introduction the moderator probed questions related to their health. The discussion has been initiated by one or two members, then it turned to the psychological problems and physical discomfort due to the illness as well as treatment modalities such as oral medications, hemodialysis, renal transplantation, dietary, and fluid restrictions and the reasons that hamper the psychological wellbeing of CKD patients has been initiated by the group members. High prevalence of psychological issues associated with CKD led to the sleeping disturbances, depression, feeling of isolation and etc. Moderator also oriented about living alone, loss of employment, high out-of-pocket expenditure and reduced economic productivity, multi-morbidity, increasing severity of illness, and stages four and five of the disease as factors significantly associated with psychological distress among CKD patients. Psychological stress due to financial insecurity in terms of per capita monthly income and out-of-pocket expenditure for health per month has been assessed and notified. Social support and coping strategies are known to reduce the distress elevated by the group members.

In addition to the social support, regular meetings with the peers and supporting each other during the illness will make them able to be supportive and reduce their stress due to CKD.

Session – II

Self Care Management

Patient-oriented self-management is the cornerstone of chronic disease management, and optimized self-management is fundamental in controlling risk factors of CKD and improving disease management especially. The group members seeking to facilitate with probing questions rather than providing a purely educational program, self-management requires patients to shift away from passive education and to become responsible for their own illness. Participants with chronic disease(s) are asked to adhere to self-management directives to limit disease progression, including regular monitoring visits for provider assessment, feedback and care-plan adjustments. As a part of the self-care management the researcher facilitated the discussion to the importance of the exercise.

Participants of the group were not aware of benefits of exercise specifically related to kidney disease. One participant acknowledged that "If I thought that it would help my kidney disease I would probably put a bigger foot forward to try to do better at exercise" (1 in the group). The members of the group reflected more often on the tangible benefits of exercise such as less fatigue and feeling better after exercise, whereas the group members those were more frequently identified the intangible benefits of exercise such as reduction in blood pressure and improved glucose control. "We should think of exercise as something that gives us energy and if we do exercise, that will give us energy" (2 women in the group).

Participants also discussed how exercise may empower them to improve their health. Several participants noted that exercise could be used as a way to make them feel they are taking control of something in their life. "You can say, 'I have this disease but it doesn't have me'" (1 woman from the group). "I would suggest to not keep thinking that you have the disease, to keep moving forward, fighting it because if you keep thinking that you are sick you get worse" (members of the group).

Participants reported that exercise is time consuming. Most participants reported lack of time as a reason they are not exercising. Many of the participants work and had difficulty finding time to exercise. "It is a time thing. Sometimes after work you get home and you just want to lie down as you are tired from work" (group 6, man). Family child care obligations were also a concern, more in women than men. Women participants discussed having to care for grandchildren as a reason for lack of time to exercise. One participant said "I don't go [work out] because of time, I take care of my grandkids and I am with them all the time" (2 members of the group).

Members of the group discussed that patient-centered care and patient self care management are increasingly advocated. Patient self care management is not only a critical mechanism through which patients can have their questions, concerns, and needs regarding kidney disease care addressed, but it is also a crucial pathway to ensuring that patients can be taught to engage in self-management of their CKD risks. Patients with CKD are charged with assimilating complex treatment regimens, including monitoring blood glucose and BP, maintaining physical activity, changing eating patterns, adhering to complicated medication regimens, and avoiding nephrotoxins. To implement these activities and participate in care decisions and planning, patients with CKD must have knowledge of their condition and self care management support (SMS).

Self care management includes innovative approaches for people with CKD exist, including self-management support, shared decision making, use of digital media, engaging families and communities. Education efficiency may be increased by focusing on people with progressive disease, establishing interdisciplinary care management including community health workers, and providing education with CKD patients at individual level, community and societal level.

The researcher also observed that all the group members were actively participated in the discussion process and the members are also feeling happy about the participation in the groups about their health aspects.

Session -III

Poor Access To Health Care Services

Access to health care has been defined as "the timely use of personal health services to achieve the best possible outcomes." Barriers to health care access prevent high-quality care from achieving expected positive clinical outcomes. Understanding the barriers to CKD care may provide information to allow policy changes that can favorably improve current standards of care, particularly health care delivery and utilization. In addition, health care access for patients with CKD at earlier disease stages, when opportunities to halt or slow disease progression may exist, could emerge as the most important area for intervention. One of the member from the group stressed and discussion on lack of health insurance, health care continuity and/or high out-of-pocket medical expenses are barriers to accessing health care and adhering to life-sustaining treatment regimens of many people with CKD.

The group members of the FGD lead the session on causes which have imped them to access health care. Barriers to health care access affecting patients, physicians, and the health care delivery system complicate the management of almost every chronic disease cases. Lack of health insurance and perceived difficulties were observed in obtaining lower health care utilization which are inconsistent with inadequate access to health care, are more likely for participants from the group with previously diagnosed co-morbid conditions.

It is undoubtedly difficult to manage a complex disease such as CKD with less than optimal health literacy and numeracy skills. Health literacy, health numeracy, and the related lack of accessible CKD information are major barriers to CKD patient education. Poor health literacy is associated with decreased CKD knowledge and kidney function. In the ESRD population, low health literacy is associated with lower rates of kidney transplantation, poorer BP control, decreased self-management, more frequent hospitalization, and increased mortality. Health literacy, health numeracy, and the related lack of accessible CKD information are major barriers to CKD patient education.

Group members highlighted the differences in CKD awareness, health care utilization, sources of care, health insurance status, and medication coverage across different stages of CKD. The researcher (Moderator of the Group) also noticed discrepancies in health care access in patients with CKD by their chronic health conditions. These results suggest that a substantial need remains to improve access to medical care in patients with CKD without insurance.

Lack of health insurance and perceived difficulty obtaining medical care with lower health care utilization, which is consistent with inadequate access to health care are more likely from the group with previously diagnosed co-morbid conditions. Involvement of nephrologists at all CKD stages remains poor and does not significantly improve with better access to health care. Thus, screening activities may provide a route to increase awareness of CKD and improve timely utilization of nephrology care, which currently represents the best chance to reduce the global burden of CKD-related morbidity and mortality.

Session-IV

Social Support

Social support refers to the network of people who exchange emotional, informational, and/or material assistance with individuals. Patients with chronic disease may receive support—including resources, information/advice, or empathy/understanding—from a variety of sources, including spouses, family members, healthcare providers, community members, members of faith-based groups, and fellow patients. Social support is usually provided by family, friends, co-workers, spiritual advisors, health professionals, and members of one's community. Important elements of support are quantity of the supportive network, frequency and reciprocity of supportive interaction and type of supportive interventions.

Understanding that patients with CKD require different types of social support which has important clinical implications. Clinical care providers could tailor intervention programmes to improve social support based on patients' needs, such as recommendations to appropriate programmes like self-help groups or psycho-educational programmes designed to promote self-efficacy in coping with dialysis. Besides providing relevant medical information regarding lifestyle changes due to dialysis, clinical care providers should also highlight to patients and family/caregivers the relational dynamics involved in lifestyle changes. Patients and their family/caregivers could be made aware of potential conflicts that could arise when communicating encouragement and support for lifestyle change.

The moderator during the session facilitated about the social support system among the members which was observed that the link between social support and health outcomes is well established across numerous illnesses.Regarding perceived social support revealed by the group members during the session, most CKD patients showed satisfaction. It is worth mentioning that, perceived social support, specifically the emotional social support, most of the group members reported that they were satisfied regarding the availability of listening, attention, information, esteem, companion and emotional support with their family members at the same time it is to accept that majority of their families and neighborhood are also affected with the same. In relation to the instrumental social support, majority of the group members reported they were dissatisfied with the availability in management and resolution of operational issues of insufficient treatment or health care, practical activities of daily living and material and/or financial assistance were very poor.

CONCLUSIONS & RECOMMENDATIONS

Ensuring that patients receive the educational support that they need as their disease progresses requires innovative approaches that target patient, provider, and system barriers. Effective education strategies exist but are not yet incorporated into routine care. Incorporating such strategies will require innovative approaches to CKD education, increased efficiency of education approaches, and policies and research to expand our capacity to provide effective patient education.

Focused group discussions aimed at improving exercise should incorporate exercise counseling and perhaps exercise prescriptions by providers. Increased engagement by providers will provide improvements in patient knowledge and self-efficacy. Additionally, providers may be able to help better utilize the health care services and to increase the social support for the patients with CKD may lead to improved outcomes.

REFERENCES

1. Eknoyan G, Lameire N, Eckardt KU. Kidney Disease Improving Global Outcomes (KDIGO) CKD Working Group. KDIGO 2012 clinical practice guidelines for the evaluation and management of chronic kidney disease. Kidney Int. 2013;2:1-163.
2. Kitzinger, J. (1994). The methodology of focus group interviews: the importance of interaction between research participants. Sociology of Health and Illness, 16, 103-121.