

Haemodialysis Patients' Perception of NKF Education Rehabilitation Programme

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Abstract

This qualitative study served as a programme evaluation to determine how the National Kidney Foundation's (NKF) patients with end-stage renal disease (ESRD) benefitted from their Education Rehabilitation Programme, which consisted of Education @ DC and Back-2-School Workshops. A focus group consisting of 12 Patient Advocates was formed to discuss the effectiveness of the programme. The results were interpreted using Interpretative Phenomenological Analysis (IPA). It was concluded that the programme was a good initiative to engage nurses to provide rehabilitation programme for patients through education, as the knowledge taught was useful and important to the patients. The programme also had a positive impact on the patients' behaviour and lifestyle habits. Further quantitative studies could be conducted to achieve more conclusive results about the effectiveness and impacts of the programme. Key variables may include as the patients' perceived impact of ESRD education, and the perceived and actual impact of education on patients' physical health.

Keywords: rehabilitation, education, haemodialysis, end-stage renal disease (ESRD)

Patients with end-stage renal disease (ESRD) have several severe limitations: low physical fitness (Bennett et al., 2010), psychological problems (Khalil, Lennie, & Frazier, 2010), and poor quality of life (QOL; Yang et al., 2015). The National Kidney Foundation (NKF) aimed to tackle these limitations based on Life Options Rehabilitation Program's "5 E's" of renal rehabilitation (i.e., encouragement, education, exercise, employment and evaluation; Life Options Rehabilitation Advisory Council (LORAC), 1998), which enables patients to improve their overall well-being (Jehan, Lobna, & Enshrah, 2012).

The current research was a qualitative post-programme evaluation of the Education Rehabilitation Programme, conducted by NKF from 4 October 2016 to 8 October 2017, and consisted of two programs: Education @ Dialysis Centre (DC) and Back-2-School Workshop. Education @ DC was a program conducted at NKF's dialysis centres across Singapore, whereby education modules were disseminated by trained nurses to haemodialysis ESRD patients. It aimed to educate patients regarding mental illnesses, insomnia, ways to living a healthy and active lifestyle, and community resources that were available for the patients' engagement. Back-2-School Workshops were held quarterly at the NKF Auditorium for haemodialysis (HD) and peritoneal dialysis (PD) patients and their caregivers. It promoted lifelong learning, a gateway for a healthier and more enriching life, and aimed to improve the health of patients through the education of personal grooming, nutrition and diet, insomnia, and medication. Comprehensively, the Education Rehabilitation Programme aimed to empower and equip renal patients with knowledge of ESRD and skills for self-reliance (Tsay & Hung, 2004), thereby

increasing their self-efficacy and allowing them to partake greater responsible for their own self-care (Lingerfelt & Thornton, 2011). Thus, the programme may also subsequently reduce stress on the patients' caregivers and communal support.

Therefore, this qualitative study aimed to serve as a programme evaluation on three aspects: (1) the benefits of the programmes on NKF haemodialysis patients, (2) the elements of the programme that had benefitted these patients, (3) the kind of impact the programme might have had on the patients' behaviour and lifestyle habits. Additionally, we sought to provide suggestions for key variables in future quantitative studies.

Method

Education Rehabilitation Programme Education @ DC

Procedure and participants

The Education @ DC programme lasted for a year, with an education module rolled out every three months. There were four education modules in total, disseminated by the nurses in sequential order. Nurses who had undergone prior training as educators provided one-to-one module education sessions with patients during their dialysis session. Ethical approval for this study was granted by NKF (Singapore) Management team has approved this study after a series of review by the allied health team. Participants were haemodialysis (HD) patients at the NKF clinic who completed all four education modules in sequential order, and gave verbal consent to participate in the programme. Exclusion criteria for participants consisted of patients who had a mental disability or illness (e.g., dementia or delirium), as the programme would not be effective for them because

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of factors like low learnability and self-efficacy. The completion rate of the programme was 63.7% (based on 3,420 patients).

Materials

There were four education modules which were disseminated in sequential order during the Education @ DC programme.

Firstly, the Beautiful Mind education module promoted patients to look after their mental health, as the journey battling a long-term illness like kidney failure is challenging. Patients may harbour worries and stress about the impact ESRD has on their life, their family and finances, which may lead to anxiety and depression. Hence, this booklet helped patients to understand and identify the signs of anxiety and depression, and guided them in self-care while nurses and counsellors continued to support them. The booklet was divided into two sections, discussing anxiety and depression respectively. In the first section, it identified what anxiety is to the patients. Patients are assured that it is normal to be overwhelmed by stress, and are advised to seek help should excessive stress cause them anxiety problems. This section also identified common causes of anxiety in kidney patients, such as feelings of being a burden to family, disease progression, financial worries, side effects of treatment, and uncertainty about the future. Additionally, physical and mental

symptoms of anxiety were listed for the patients' reference. Patients are cautioned that different people may experience different kinds of symptoms of anxiety, and side effects of dialysis may be similar to anxiety symptoms; though patients are encouraged to alert their nurse any time they experience any of these symptoms. Finally, tips were given to patients on how to manage anxiety, like having positive thoughts, reducing caffeine intake, turning to loved ones and members of their community (i.e., nurses, counsellors and healthcare professionals) for support and comfort, and practicing a breathing exercise that was explained in detail in the booklet.

In the second section, the definition of depression was explained, and the possible causes of depression for ESRD patients were listed, such as the prevalence of life events (e.g., unemployment or losing a loved one) and the onset of life-threatening or chronic illness. Patients were given a checklist of symptoms to recognise depression, and were recommended to seek help if they experienced five or more symptoms. In this booklet were tips on how to manage depression, one of which was acknowledging that it is not easy to get assistance for depression due to feelings of shame or fear of familial judgment and disapproval. Patients were encouraged to continue engaging in meaningful activities and receiving proper forms of help. Hotlines for the patients'

reference were included in the last page, including organisations that provides counselling and mental health treatment.

Secondly, the Quality Sleep education module educated patients on ways to cope with insomnia. It stressed that sleep is fundamental in recovery and well-being, which many kidney patients lack due to insomnia; which could lead to sleep disorders and low QOL. This module delved into insomnia by explaining insomnia and its ill effects; and provided possible explanations as to why a patient may be experiencing insomnia, such as body aches as a side effect of dialysis, mental issues, substance abuse and smoking, poor diet, inadequate dialysis causing discomfort due to a build-up of waste in a patient's blood, or excess fluid in the person's body, causing chest discomfort and breathlessness. The booklet advised patients to discover if they have insomnia by visiting a doctor, who may diagnose patients based on their medical and sleep history. It also advised on ways to manage insomnia through good sleep hygiene practices, which their nurses could help them with. It also encouraged patients to keep a sleep diary that helps with identifying their sleep patterns and understanding possible reasons for bad quality sleep, which may hence assist nurses in the creation of a suitable intervention plan for the patient. Helplines for organisations dealing with mental

...the Healthy Lifestyle education module promoted patients to maintain an active life of work, quality time with family and friends, and physical activity through changes in diet and lifestyle choices.

excessive worries that would otherwise lead to negative thoughts and behaviours, interfering with their desired lifestyle and increasing their desire for substance abuse. Living Smart helped patients to identify the three challenges that they could seek help for – psychological challenges (i.e., mental health and emotional stress), social challenges (i.e., need for financial assistance and family matters), and physical challenges (i.e., rehabilitation needs, mobility issues and medical assistance). The module recommended NKF as the patient's first line of support, with its various services that it provides for the holistic care of its patients and their family. Patients were made aware that NKF provides psychosocial support and counselling by a team of medical social workers and counsellors, and is readily available to assist in overcoming a patient's psychological and social challenges. Patients were also told that peer support through patient advocacy is another service which NKF provides, through which encouragement and comfort can be shared by fellow patients during their rehabilitation. Additionally, patients were notified that NKF's dietician may provide diet and nutrition advice to patients, to improve the patient's

self-efficacy in having a better diet and preparing healthier meals. Also stated were NKF's occupational therapists which are available to guide patients with disabilities to improve their physical functioning and mobility in their homes and outdoors. Finally, patients were enlightened on NKF's weekly exercise classes and videos, developed by their exercise specialists, which is provided as a secondary form of treatment. This is because exercising may help patients to strengthen their hearts and muscles, which could allow them to overcome their physical challenges. Moreover, it is beneficial in helping them lose excess water. The last section of Living Smart expanded on other organisations which could provide psychological help and financial aid; and provided hotlines for social assistance, psychiatric emergencies, crisis support, care services and legal support.

Back-2-School Workshop

There were 300 participants per workshop, who were haemodialysis and peritoneal dialysis patients and their caregivers. The workshops were advertised through posters, and patients registered through their nurses on a first-come-first-serve basis if interested.

Four Back-2-School Workshops were held quarterly at the NKF Auditorium. The first workshop, titled Personal Grooming, was conducted by an image consultant, and focused on educating patients to boost one's confidence and appearance. Topics focused on grooming and dressing tips according to individuals' hairstyle, face and body shapes. The second workshop, titled NKF MasterChef, was a cooking competition conducted by NKF's in-house dietitian, and it focused on improving patients' knowledge on nutrition and the importance of having a healthy diet. The third workshop, titled Working Towards Quality Sleep, discussed insomnia and ways to combat the problem. The fourth and final workshop, titled Medication & Its Effects, encouraged patients to take an active participation in understanding their own health and medication that they are prescribed.

Post-Programme Evaluation

Participants and Procedure

An hour-long focus group discussion was conducted to determine the effectiveness of the Education Rehabilitation Programme. The researchers acted as facilitators for the focus group. NKF's Community Support Services team purposefully selected 12 NKF Haemodialysis patients, under the

patient advocacy programme, from 11 dialysis centres across Singapore, average age of 58 years old, six males and six females. These participants reflected the age group of the main patient population and were undergoing haemodialysis at the time of the focus group.

Before discussion, participants were briefed on the purpose of the study, and verbal informed consent was given by participants.

Data analysis

Interpretative phenomenological analysis (IPA) is a psychological qualitative approach which aims to provide detailed examinations of personal lived experience in the given context, and makes sense of the given phenomenon. It produces an account of lived experience in its own terms rather than one prescribed by pre-existing theoretical preconceptions. IPA is a particularly useful methodology for examining topics which are complex, ambiguous and emotionally laden. It is a good for a group study between three and 15 participants.

The main facilitator gathered qualitative data from participants during the focus group using flexible and open-ended questions on participants' experiences of the education programme. Detailed verbatim transcript was recorded and transcript by the co-facilitator. Three main themes that were brought up during the focus group were identified.

Results and Discussion

There were three main points were brought up in during the focus group discussion – the usefulness and importance of the educational programme, the delivery of the education materials, and having a patient-led programme.

Firstly, the Educational Rehabilitation Programme was useful and important to the patients. There was a consensus among participants that sufficient information was provided during Education @ DC and in the Back-2-School Workshops. Participants also agreed that the programme was essential for patients who originally had little to no awareness of the topics covered. The knowledge gained from the programme had been applicable to the patients – helping them in their improvement of sleep quality, engaging in meaningful conversation with healthcare professionals (e.g. their doctors, nurses and dieticians), and personalising their rehabilitation treatment. It also assisted them with customising their medical treatment, effectively increasing their

protein intake (after learning about the importance of maintaining muscle mass), and looking forward in life and proactively seeking help when needed (e.g. seeking help from an occupational therapist regarding their mental well-being).

To value-add in the applicability of the educational programme, patients suggested that a pocket-sized FAQ booklet containing of a brief summary of knowledge could be dispensed during the programme for convenient referencing on the go. On another note, although the Back-2-School Workshop had been a good platform to engage patients, it was limited to a maximum of 300 beneficiaries per session (including haemodialysis and peritoneal dialysis patient's family and friends) due to the venue's holding capacity. Also, it may have been inconvenient for patients with poor mobility to travel to the venues.

Secondly, participants suggested that the delivery of materials in Education @ DC could be improved. Adequate training had not been given to the nurses and the consistency of trainings remained an issue despite having a standardised curriculum and briefing for them. Moreover, nurses in clinics that concurrently catered to a large number of patients were too busy to provide effective one-to-one sessions with each patient. Thus, some nurses decided that patients who were intellectually capable of understanding the materials on their own did not require one-to-one sessions, and simply handed the education modules to them. As a result, these patients were unmotivated to read the education modules as they did not see the importance in doing so.

Furthermore, there had been a language barrier between several patients and nurses. As most nurses at NKF's dialysis centres are foreign nurses. Thus, these nurses had difficulty in conversing with patients when expressing ideas and clarifying terms from the education modules to non-Chinese patients (e.g., Malay and Indian patients). Other language barriers were present with special populations of patients, such as Punjabi patients and patients of the pioneer generation who uses their mother tongue (i.e., Chinese dialects, Malay, Tamil, Hindu etc.). Therefore, these challenges had caused nurses to face difficulties in providing in-depth education to the patients during Education @ DC. To increase the effectiveness of comprehension for the non-English and pioneer patients, the focus group suggested to produce educational booklets in languages other than the ones already

available (e.g., Malay, Tamil, etc.). However, NKF feels that it would not be cost effective to produce and print extra booklets on a large-scale basis.

Thirdly, participants ideated on a patient-led programme that would allow Patient Volunteers to be trained as Education Facilitators to conduct the Education @ DC programme instead of nurses. This would decrease the workloads of the busy nurses, and allow patients to have longer and more in-depth one-to-one education sessions. This would also allow for better educator-patient interaction, as fellow patients would be better able to genuinely relate and empathise with each other. Hence, patients would have a higher willingness to take the advice of educators, as they feel connected and understood by these Patient Advocates, as compared to professionals such as doctors and nurses who have not been through their situation. Thus, it could tackle problems where patients refuse to listen to the nurses' and doctors' advice. Additionally, Patient Advocates may better relate to other ESRD patients as they have a similar cultural background, compared to the foreign nurses who are unfamiliar with the country's culture. Thus, they would be able to better translate certain concepts to patients in their own colloquial language, and share self-care tips that they have gained through experience with their fellow patient (which will be more relatable to patients as compared to advice given by professionals which are highly theoretical). Furthermore, Patient Volunteers can solve the problem of a language barrier between nurses and patients, as they are able to speak the local language. They could conduct one-to-one sessions with the special population of patients that do not converse in English or Mandarin, and therefore increase the effectivity and patient understanding in the education sessions.

Limitations

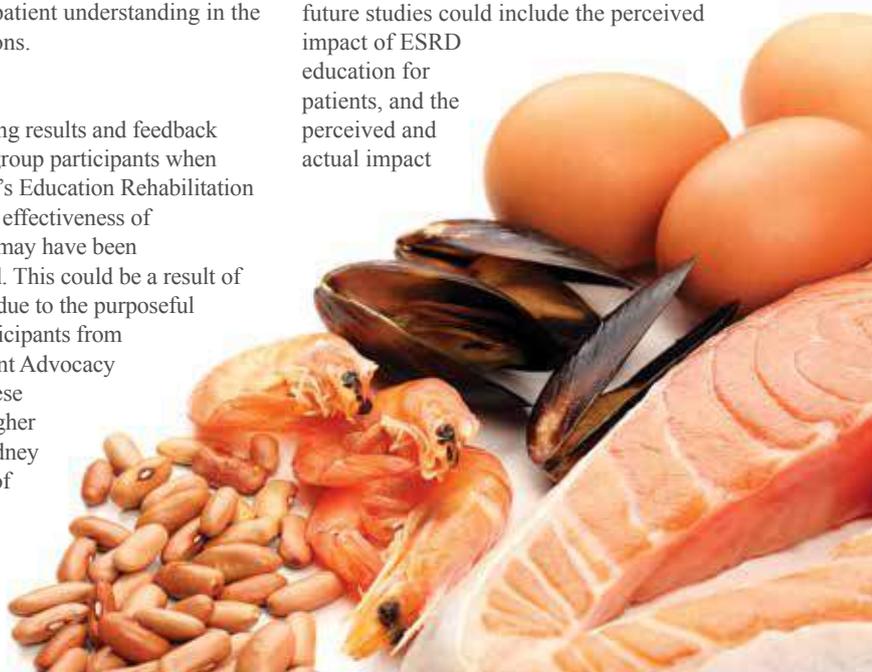
Despite promising results and feedback from the focus group participants when evaluating NKF's Education Rehabilitation Programme, the effectiveness of the programme may have been overexaggerated. This could be a result of a selection bias due to the purposeful selection of participants from the NKF's Patient Advocacy programme. These patients have higher scores on the kidney disease quality of life (KDQOL)

measure – a health survey that assessed the quality of life of a patient with kidney disease (Hays, Kallich, Mapes, Coons, & Carter, 1994), meaning that they have an improved overall well-being as compared to the general population of ESRD patients. They also have better physical health than the general population. These are possible reasons as to why they are able to volunteer as advocates and engage in community work. Thus, they may overlook problems that patients with worse overall well-being and lower mobility may face, and portray an overexaggerated depiction of the magnitude of positive impact of the programme on haemodialysis patients with ESRD.

Furthermore, researchers question if there had been miscommunication and misconceptions with the delivery of research questions during the focus groups. Researchers noticed that some participants had been confused with questions given by the facilitators, and some had provided answers that were not relevant to the questions. Thus, we suggest that a pilot test could be done in the future to practice the delivery of research questions and prevent these errors in the actual testing phase.

Future Studies

Quantitative research could be conducted to achieve more conclusive results about the effectiveness of the Education Rehabilitation programme and understand more about its impacts as well. Quantitative studies will have a larger sample size, thus they will have higher power in determining the validity (i.e., by finding out what we should be testing) and reliability (i.e., by having concrete quantitative results to support current research) of the Education Rehabilitation Programme. Possible key variables of future studies could include the perceived impact of ESRD education for patients, and the perceived and actual impact



of education on patients' physical health. However, further qualitative studies will firstly be needed to determine other key variables for these quantitative studies.

Additionally, qualitative research on nurses' perception of NKF's Education Rehabilitation Programme could be done to increase the effectiveness of the Education @ DC programme. This could identify areas of the training programme that are lacking or are not successful and identify the nurses' thoughts on the Volunteer Educators.

Cultural considerations must also be noted when using the KDQOL, a Western instrument, to determine Singaporean ESRD patients' overall well-being. Chow and Tam (2014) explained that standard items on KDQOL may differ in application across countries. Thus, the KDQOL should be revised to fit the Singaporean context. Also, the relationship between KDQOL and education rehabilitation in local context could be explored further.

It may also be necessary to review the Education Rehabilitation Programme syllabus. There currently exists a lack of control with regards to the consistency of delivery in Education @ DC, in terms of quality of delivery and patient education, styles of delivery across nurses, and centre culture across Singapore. We do acknowledge that methods of delivery differ in effectiveness across centres. Thus, further research need to be done to determine what method of delivery works best in each centre, and how we should standardise syllabus delivery by nurses across centres. Another concern is that the Education @ DC's education modules were produced by researchers. Therefore, the perspective may not match the patients', and the information provided may not be highly valid. It is not certain whether the topics covered are those that are most important to current ESRD patients. Hence, an alternate focus group could be conducted to identify patient's immediate

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needs. Additionally, an increase in patients' knowledge does not necessarily create a positive change in their well-being if no action is done. Thus, we have to come up with ways to ensure that patients are enforcing the knowledge that are taught to them during the programme. However, it should be noted that the review of the syllabus should not compromise on the quality and consistency of the content.

Conclusion

Results prove that this new education programme was a good initiative to engage nurses to provide rehabilitation programme for patients through education. The education provided to haemodialysis patients was useful and important to them, and was essential for patients who had little awareness about insomnia, comorbid mental illnesses, dietary and physical health, and ESRD medication. The programme also had a positive impact on the patients' behaviour and lifestyle habits.

Explicitly, it helped in the improvement of sleep quality, proactive engagement in their rehabilitation process, and gave them a forward-looking perspective. Further quantitative studies could be conducted to achieve more conclusive results about the effectiveness of the Education Rehabilitation programme and understand more about its impacts as well. Key variables may include as the patients' perceived impact of ESRD education, and the perceived and actual impact of education on patients' physical health. 📌

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