PRE-DIALYSIS EDUCATION PROGRAMME
Executive Summary

[Adapted from the report by DR. NUR FARHANA MOHAMAD]

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Introduction

Chronic Kidney Disease (CKD) is a growing public health concern which is responsible for various complications including all-cause and cardiovascular mortality, progression to end-stage renal disease (ESRD), cognitive decline, anaemia, mineral and bone disorders. The Global Burden of Disease 2015 study estimated that, in 2015, about 1.2 million people died from kidney failure, an increase of 32% since 2005. In Malaysia, the prevalence of CKD has increased from 9.1% in the 2011 Malaysian National Health and Morbidity Survey to 15.5% in 2018. The number of patients with CKD is expected to significantly rise in the future largely due to the increasing prevalence of diabetes, hypertension as well as the aging population in Malaysia.

It is known that timely referral to nephrologist is recommended for renal replacement therapy (RRT) in people with progressive CKD. In the Malaysian Clinical Practice Guideline (CPG) for Management of Chronic Kidney Disease (Second Edition) 2018, it is stated in the recommendation that CKD patient with rapidly declining renal function (stage 4 to stage 5) should be referred to a nephrologist/physician. The UK Renal Association recommends that all patients with severe CKD (stage 5 and progressive stage 4), alongside their families and carers, should be offered pre-dialysis education programme (PDEP).

This programme aims at improving knowledge and understanding of the condition, as well as assisting them in making decisions for RRT. However, in most studies, it is reported that about 40% to 60% of patients with CKD start dialysis in an unplanned fashion and/or under urgent circumstances despite regular follow-up by a nephrologist. This is of concern since in unplanned dialysis, patients forego the opportunity to make an informed, shared decision regarding the timing and modality of RRT as options for RRT under urgent conditions are often limited. This highlights the importance of a structured and comprehensive PDEP in preparing advanced-stage CKD patients for RRT.

At present, there is no standard national programme established in Ministry of Health for pre-dialysis education. Pre-dialysis education for advanced CKD patients is often done in different ways across the country. Effectiveness of such methods in delivering pre-dialysis education for advanced CKD patients is largely unknown. Therefore, this health technology assessment (HTA) was requested by Head of Nephrology Services, Ministry of Health, Malaysia to review the available evidence and feasibility of structured PDEP for advanced CKD patients before its adoption into national programme in Malaysia.

Technical features

Pre-dialysis education programme (PDEP) often described as multidisciplinary education programme, which consists of multiple education sessions where patients are educated by three or more health care professionals such as nephrologist, nurse, dietitian, medical social officer, home-dialysis coordinator, pharmacist, technician, or by other dialysis patients. This programme usually caters CKD patients who are in stage 4 and 5. There are variations in practice, however, PDEP usually includes individualised one-to-one sessions with a member or members of the multidisciplinary team and group discussions, peer counselling as well as problem-solving sessions have been described. The aims of this programme are mainly to provide patients with information on ESRD treatment options, help decision-making between treatments, and encourage self-care to improve quality of life.

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Policy Question
Should a structured PDEP be expanded in all Ministry of Health facilities?

Objective/Aim
The objective of this health technology assessment is to assess the effectiveness, safety, organisational, ethical, legal, societal implications, cost-effectiveness related to PDEP for advanced CKD patients and to assess the most suitable PDEP for Malaysian context.

Results and Conclusions
A. SYSTEMATIC REVIEW OF LITERATURE
A total of 251 records were found to be potentially relevant and were screened using the inclusion and exclusion criteria. Sixteen out of 75 full text articles comprised of one SR with meta-analysis, one SR, one RCT, three cohort studies, two retrospective cohort studies, two pre- and post- intervention studies, four cross-sectional studies and two qualitative studies were finally included in this review. All studies included were published in English language between 2003 and 2018. Most studies were conducted in Taiwan, United States of America (USA) and Europe. Others were conducted in Brunei, The Netherlands, Turkey, Canada, Philippines and United Kingdom (UK).

Effectiveness
There was limited fair level of retrievable evidence to suggest that participation of advanced CKD patients in PDEP contributed to greater survival probability and higher one-year survival rate compared to those who did not. However, no significant difference reported after two years. Limited fair to good level of retrievable evidence to suggest lower mortality and morbidity rates in patients who had PDEP. Limited evidence demonstrated that patients who had PDEP had longer time to dialysis and better blood profiles compared to those who did not. Significantly lower peritonitis-related mortality rates and lower peritonitis-related morbidity rates were also noted in PD patients.

Safety
There was no retrievable evidence on the safety issues with regards to PDEP for advanced CKD patients.

Organisational
Hospitalisation / Length of stay
There was fair to good level of retrievable evidence to suggest that PDEP was associated with significantly lower frequency of temporary catheter use, lower rates of hospitalisation at dialysis initiation and post- dialysis, as well as shorter length of hospital stay.

Components of programme
The evidence showed great variation in the components of the programmes described, from the multidisciplinary team members, to the educational process including timing, delivery styles, formats for content, structure, conduct of the programme and materials. However, most evidence reported involvement of multidisciplinary team members almost always comprised of nephrologists, nurses, dietitians and medical social officers, with few had pharmacist, clinical psychologist and patient volunteers. Most studies mentioned multiple individual sessions with few had mixed of individual sessions and group sessions as well as patients' involvement. Majority involved patients with CKD stage 4 and 5 in the programme, with content tailored according to the patients' CKD stage and principally focused on knowledge on nutrition, lifestyle modification, nephrotoxin avoidance, compliance to medications, preparation for RRT and modality choices with few reported hands-on and demonstration. Materials used ranged from video materials, printed materials, and website materials. Frequency of the sessions and

follow-up were mostly depended on the CKD stage.

Guidelines

Few guidelines from UK, USA, France, Europe and a position statement following an expert meeting in Switzerland have been issued outlining the recommendations on the conduct of PDEP.

Social/Psychological

There was fair to good level of retrievable evidence to suggest significant association between PDEP and patient's choice as well as receipt of PD and home dialysis for RRT. Limited evidence also showed higher rates of pre-emptive kidney transplantation rates, higher levels of knowledge of ESRD and RRT options as well as higher levels of adherence, lower depression levels and anxiety levels, and better HRQL were noted in patients who had PDEP.

Limited evidence also showed that patient factors including individualisation, educational factors including tailored education, appropriate time/information, and available resources as well as support systems were the influential factors on patients' decision for RRT. Sub-optimal education, different perspectives between patients and staff, and the influence of patient experience were the three themes identified which related to improving PDEP.

Cost-effectiveness

Based on two cost-analyses, significant reduction in medical expenditure after initiation of HD were noted in patients who had PDEP and the cost-saving effect came through the early preparation of vascular access and reduced hospitalisations.

B. LOCAL SURVEY ON PRE-DIALYSIS EDUCATION PROGRAMME

A multi-centre cross-sectional questionnaire survey was conducted in January 2020 to identify the essential components of pre-dialysis education programme based on the preferences of patients, carers and healthcare workers. A total of 39 respondents were recruited via purposive sampling from three public hospitals. Based on the survey findings, patients and carers preferred to have a 30-minute single session with multiple educators every three months delivered by a multidisciplinary team consisting of doctor, dietitian, patient representative, medical social officer, psychologist, pharmacist, nurse and medical assistant with a mix of education materials such as hands-on session or demonstration, audio-visual aids, leaflets or pamphlets and information about websites or online videos in the hospital setting. The pre-dialysis education may be given as an individual (one-to-one) or group session depending on the patient's preference. The pre-dialysis education should be initiated approximately six months before starting treatment of choice, allowing patients and carers to have sufficient time to understand about available treatment options. Patients and carers agreed that being part of a patient support group would be helpful in solving real-life problems and that shared decision-making between doctors and patients is important to them. The healthcare workers expressed different preferences in terms of delivery method, time of initiation, duration, frequency, and venue which may arise from consideration of practical aspects such as daily burden of workload and capacity in delivering the education sessions, which should be taken into consideration when designing the PDEP.

Recommendation

Based on the above review, a standardised approach to PDEP should be outlined before its expansion to all Ministry of Health, Malaysia facilities. A multidisciplinary team involving well-trained personnel, and optimally with mixed individual and group sessions as well as using interactive mixed education materials should be established. Comprehensive and more personalised content tailored according to the CKD stage taking account individual needs, emotional support, psychosocial aspects, involvement of family as well as caregivers and additional support from patients' support group are advocated.

Methods

Studies were identified by searching the electronic database for published literatures pertaining to PDEP for advanced CKD patients. The following electronic databases were searched through the Ovid interface: Ovid MEDLINE® In-process and other Non-indexed citations and Ovid MEDLINE® 1946 to present, EBM Reviews - Health Technology Assessment (4th Quarter 2016), EBM Reviews - Cochrane Database of Systematic Review (2005 to Dec 2019), EBM Reviews - Cochrane Central Register of Controlled Trials (Dec 2019), EBM Reviews - Database of Abstracts of Reviews of Effects (1st Quarter 2016), EBM Reviews - NHS Economic Evaluation Database (1st Quarter 2016). Parallel searches were run in PubMed and INAHTA database. No limits were applied to the search. Detailed search strategy is as in Appendix 3. The last search was performed on 2nd December 2019. Additional articles were identified from reviewing the references of retrieved articles.