



Service Priorities and Programmes Electronic Presentations

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Empowerment Programme for epilepsy Patients- Pilot Project on Enhancing Self Management

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Introduction

Epilepsy is a neurological complex of cerebral dysfunction. Statistics show there are an estimated 40,000 (5-6%) people with epilepsy in Hong Kong. Despite the advances of neuro-pharmacology in the past decades, the cure rate of epilepsy is still low and about 30-40% of the patients cannot reach seizure free. A recent study in 2012 by The Hong Kong Society for Rehabilitation and Hong Kong Epilepsy Association revealed that 80% patients with refractory epilepsy spend less than five minutes in their follow-up consultations. Most of the patients are in need of medical and other support because they have low level of confidence about self -managing their conditions. As the literacy level of residents in NTWC is relative low, measures to enhance their knowledge on managing epilepsy is very important. However, patients spend less than five minutes in their follow-up consultations because there are too many waiting to be seen.

Objectives

To enhance patient with patient with preliminary knowledge background they need to have To start with the concept of some self management and extend their social supporting circle Prepare them to pursue the information about epilepsy and thus enhance communication with doctors about their problem and the more complicated treatment options like AED uses or epilepsy surgery To pilot a hospital and community collaboration on epilepsy

Methodology

Multidisciplinary including, nurse, psychiatrist, clinicopsychologist, occupational therapist, social worker, community worker, physician Not too frequent per year ~ 3-4

times per year Scheduled in office hours to ensure every one's availability Relatively short duration of talk- to balance between the numbers of topic coverage and the concentration of our patients/relatives (very likely much shorter than normal people) All the content are based on individual expertise rather than centralised material Small group up to 20 patients per session/relatives – considerate about their special psychology in these public event. Continuous running allow patients to come back (patients with poor memory) ACTIVE recruitment- start with medical SOPD/neurology clinic for patients with new onset epilepsy or never attended epilepsy course Gives appointment sheet to them or record their contact method if date is not confirmed Phone contact for the exact date and ~ 1 week before as reminder. (Including those previously missed and not attended patients) Sign attendance with information materials including the booklet and materials from CRN Presentations one by one within 2 hours Questions and Answers time Evaluation form signed before their leave

Result

An effective mechanism of referral system has been established. 103 subjects with epilepsy and their relatives were recruited and 67 participants completed the evaluation questionnaires were received. 22% and 76 % of participants were very satisfied or satisfied with the programme respectively. 93% of participants believed that their knowledge of epilepsy was improved after participating the talk. Participants showed interest in the following topics, including healthy life style (36%), stress management (51%), medication treatment (54%) emotional management(56%) and how to improve memory (38%). 96% of the participants replied that they were willing to participate relevant talk about epilepsy in the future. Besides, some of the participants suggested the talk should provide more detail information on epileptic medication and how to define the progress of epilepsy.