REVIEW

THE FEASIBILITY, AWARENESS, KNOWLEDGE AND ATTITUDES TOWARDS ANIMATED EPILEPSY EDUCATIONAL VIDEO (ANEEV) AMONG FAMILY CAREGIVERS

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ABSTRACT

The educational needs of epilepsy family caregivers vary depending on their relationship to the patients, their role in providing care and their emotional needs. Carers often have lack of confidence in their ability to seek information, resulting in barriers to receive information. Various educational programmes / materials about epilepsy were designed to improve the awareness, knowledge and attitudes (AKA) of patients and their families. Therefore, this study aimed to assess the feasibility, acceptability and practicality of Animated Epilepsy Educational Video (AnEEV) and AKA of family caregivers (FCGs). This part of a randomized, controlled study included a sample of 32 epilepsy FCGs who were recruited from the Neurology and Paediatric Clinics of Hospital Sultanah Nur Zahirah (HSNZ), Kuala Terengganu. Descriptive statistics were employed for data analyses (SPSS 17.0). Most were women (59.46%), married (65.6%), earning between RM1001 - RM2000 (34.4%), receiving secondary level education (65.6%) and were patients' parents (65.6%). The AnEEV was highly acceptable (97.0%), easy to understand (90.9%), attractive (93.9%) and useful (87.9%). Almost all carers recommended AnEEV to other carers (97.0%) and were hoping to receive such educational materials in the future (93.9%). The Total AKA score was generally good (median=125.0; range=75.0-155.0) with awareness being moderate (median=30.0; range=0.0-50.0), knowledge was good (median=60.0; range=40.0-75.0) and attitudes were positive (median=35.0; range=10.0-40.0). The overall outcomes signified that AnEEV were well-received by the family caregivers and these favourable findings suggested that AnEEV could help in improving AKA for carers, which could ultimately assist epilepsy treatment, management and rehabilitation process

Keywords: *Animated epilepsy educational video; acceptability, feasibility, carers*

INTRODUCTION

In response to the needs in epilepsy caregiving, it is of paramount importance that the awareness, knowledge and attitudes (AKA) levels are enhanced among carers in order to allay fears and mistrust about this illness [1]. Outcomes from previous research have revealed positive evidence from the behavioural, educational and social sciences perspectives which indicated that among others, AKA towards a particular disease are essentials to achieve independence in caregiving routine [2].

It is also not surprising that modern advances such as the integration of Information and Communications Technology (ICT) into health education possesses the potential to improve patients or carers' health-related quality of life (HRQoL) through appropriate techniques although indirectly. Better understanding certainly improves disease management and the goals could be achieved by providing the necessary skills and information to deal with daily obstacles in managing the disease condition [3].

At present, with the rapid growth and major advances in ICT, educational methods such as books, pamphlets and brochures are merely viewed as conventional and considered "out- dated" [4]. Consequently, the need to develop a new approach in providing effective educational tools for patients as well as their family caregivers (FCGs) has resulted in the integration and assimilation of variety forms of application [5] such as web-based platforms, computer software programmes, telematics and mobile gadgets [3]. Realizing the full potential of the ICT will require constant commitment to theory-driven research at basic, methodology, clinical, and applied levels [6]. Given such opportunities, a conceptual framework is needed to broaden the scope and boundaries between technology, theory and its applications in healthcare education [7]. Most recently, the Animated Epilepsy Educational Video (AnEEV) has been developed for health education and promotion in neurology.

The creation of AnEEV was a continuous innovation from the established Interactive Epilepsy Education

Programme (IAEEP) [4] for epilepsy information dissemination. Thus, this study aimed to: 1) outline the development of AnEEV, 2) determine the feasibility, practicality and acceptability of AnEEV and 3) assess the general AKA of epilepsy FCGs.

METHODS

Development of AnEEV

The development process began with an investigation into the focus of requirements of epilepsy health education for FCGs. Several established technological applications used in epilepsy and other chronic diseases health education were discovered to study the patterns of the delivery medium. Subsequently, a specific focus was set on the needs and problems encountered by epilepsy FCGs during their daily tasks. We intended to develop an animation based on these experiences to deliver beneficial information to epilepsy patients and particularly their carers to cope with their routine problems. This information was later employed as the main contents in AnEEV besides adopting some vital parts from the IAEEP [4]. A series of discussions were initially carried out between the educators and technicians for contents arrangement before AnEEV was produced. The video contents were divided into two parts; 1) narration text and 2) video. The AnEEV was then tested in epilepsy FCGs. Feedback and evaluation was crucial for implementing AnEEV as a new delivery tool in promoting health education. Refer to Fig. 1.

Contents of AnEEV

The information needed for AnEEV's contents were explored six months prior to the animation development. A total of 32 carers recruited in our previous study [8], who had accompanied their loved ones for weekly routine clinic day were approached for an interview to gain insight about caregiving for epileptic patients from the carers' perspectives. A qualitative technique was adopted to gather the information desirable as this was considered the most appropriate method to generate in-depth knowledge about caregiving experiences [9]. The FCGs' experiences including their feelings, values, meanings, problems and needs towards the epilepsy patients they were taking care of were included. Explorative interviews with guiding questions were utilised to ensure the needed data was investigated in a similar structured manner with each carers [8]. The interview questions were open-ended and broad in order to elicit detailed description of the FCGs experiences. In particular, the questions focused on their capabilities in caregiving i.e. 1) managing the patients at home, school and outdoor, 2) daily routines, 3) emotional well-being, 4) social life, 5) caregiving burden and difficulties, 6) caregiving needs and concerns, and 7) perspectives on patients in terms of health performance and condition improvement [8]. Their problems and needs were identified to be incorporated into the main contents in AnEEV in addition to information from existing literature.

Production of AnEEV

The creation of animation for AnEEV was especially emphasized. The production of 2D and 3D animation required several methods namely modelling, mapping, lighting, camera, animation and rendering. The flow of animation production was divided into three main divisions i.e. pre-production, production and post-production. During the pre-production stage, the storyboard and storyline were produced in order to finalise the cost considerations for the animation development. The production stage includes providing materials, lights and effects, animation techniques, simulation of some phenomenon, rendering and design reviews. The finishing touches were done in the post-production stage where animators edited and composited the animation. The AnEEV was made in Malay version only. This process was completed by our hired animation technician.

Structured contents of AnEEV

The AnEEV was designed to be simple and self-explanatory and it was divided into four main segments as follows;

1) Introduction:
Provides the general definition of the disorder and the basic mechanism of seizure attack.
2) Factors:
Explains about factors that could trigger seizure attack.
3) Basic facts:
Delivers basic knowledge regarding epilepsy such as usual misconception of this disorder and its safety tips.
4) Video story:
Presents the daily experiences of FCGs and patients based on actual caregiving routine. Among the scenes featured were activities at home, in school, at shopping malls and in the hospital.

The AnEEV optimises messages to help carers of epilepsy sufferers improve their AKA towards epilepsy and HRQoL, hence ensuring good quality of caregiving. The background scene and characters realistically depict daily routine of epilepsy patients and carers, whereas for the video contents, basic facts about fits and seizures, playback scenes of fits and even an actual routine life of a caregiver were included. The contents for basic facts were adapted from the IAEEP [4].

Features of AnEEV

The story in AnEEV was built in the form of visual and caption-enhanced animation to capture focused attention from viewers which could simultaneously enhance their caregiving knowledge, skills and understanding while

maintaining their overall well-being. The use of multimedia components in AnEEV such as graphics, sounds and animations as delivery tools for epilepsy patients and their carers could not only aid the learning process but also offer engaging interactions with the viewers. This innovation provides an advantage in allowing patients and their families to repetitively access and views the messages in their own leisure time, hence strengthening the sustainability of information. Besides, AnEEV is the first epilepsy animation established in Malaysia which has been used as a tool to promote health education in epilepsy.

Evaluation of AnEEV's feasibility, practicality, acceptability and FCG's AKA

Ethical and institutional approval

Official ethical approval was obtained from the Ministry of Health Research and Ethics Committee Malaysia (MREC) (reference number: KKM/NIHSEC/800-2/2/2 Jld.3.P13-686). A contact was established with the respective clinic coordinators including the staff nurses and medical assistants to discuss the meeting day, date and time for data collection. The discussion also included the list for suggested potential patients with their carers who could be the respondents along with the date and time to meet, study procedures, study duration and requirements needed from the respondents.

Study design and sample selection

The study described here represents part of a randomized, controlled parallel investigation carried out in the Paediatrics and Neurology Clinics of Hospital SultanahNurZahirah, Kuala Terengganu, Malaysia, between October 2014 and February 2015. The main respondents were chosen among epilepsy FCGs who accompany their loved ones to the hospital. The inclusion criteria for the FCGs included: 1) primary caregivers to the patients, 2) age of 18 years old and above, 3) able to understand, read, speak or write in Malay language, and 4) capable of completing the questionnaire (written or verbal). The caregivers were automatically excluded from this study if they were not the family members of the patients or have physical incapacities.

Data collection and study procedure

On the meeting day, the caregivers were initially invited into a designated room for privacy of discussion. They were provided with a thorough explanation on the study purposes and its procedure as laid out in the *Family Caregiver Information Sheet* (for FCGs). The written consent form was signed upon participation agreement by FCGs, who later proceeded to complete a set of questionnaire as follows: 1) *Personal Information Form* and 2) Malay AKA Epilepsy and 3) feedbacks questions. The FCGs were instructed to watch the AnEEV after they had completed the questionnaires during that session which lasted five minutes and twenty one second. Finally, the carers were requested for feedbacks on AnEEV. At the end of session, the FCGs were thanked for their participation.

Statistical analysis

Data was analysed using Statistical Package for the Social Science (SPSS) version 17.0 for Windows (SPSS, Inc.). All socio-demographic data and general AKA was analysed descriptively and presented as frequencies and percentages. Descriptive statistics were also used to analyse the median and range for all continuous variables. Statistical significance was accepted at 0.05 level of probability. An initial normality test, carried out utilising Total AKA score as a dependent variable, showed that normality requirement was violated (Shapiro-wilk test= $p<0.05$; data was positively skewed). Subsequently, non-parametric tests such as the x^2 for goodness of fit was employed to test for homogeneity of the proportion of categorical variables, and the Mann–Whitney U test was employed to test between-group score comparisons.

RESULTS

Sociodemographic characteristics

A total of 32 FCGs were enrolled in the study with a median age of 48.5 years old (range=19 to 66 years old). According to Table 1, the proportion of female respondents was slightly higher (59.4%) compared to males. Most of the carers were already married (65.6%), housewives (31.2%), with highest educational level at secondary school (65.6%). These carers were earning not more than RM1, 000 per month (34.4%) and majority were parents to the patients (65.6%). Significantly greater proportions of the caregivers were within the age group of 39 to 58 years old, already married, with monthly income of less than RM1, 000 or none at all and were parents. In addition, significantly more respondents (65.6%) had cared for the patient for between 1-10 years and admitted being "satisfied" with their caregiving responsibilities.

Evaluation of AnEEV

Feasibility, practicality and acceptability of AnEEV

Upon recruitment, carers were asked if they were already familiar with an animation video and all FCGs answered 'yes' to the questions indicating 100% familiarity with the delivery method of this health education programme. Based on Table 2, most carers agreed that the AnEEV was a good programme and acceptable (97.0%) as a new platform for health education. They also agreed that the contents of AnEEV were self-explanatory and the language style used was simple and easy to understand (90.9%). The FCGs contended that the

arrangement of AnEEV contents and subplots were interesting, attractive (93.9%) and useful (87.9%) for their actual experience. They were in favour of recommending AnEEV to other carers (97.0%) and were also hoping to receive such educational materials in the future (93.9%). At the end of the session, almost all carers gave assurance of their full support towards the usage of AnEEV at home.

Evaluation of epilepsy FCGs' AKA profiles

General AKA profiles

Generally, the Total AKA level of epilepsy carers who visited HSNZ was considered good with scores ranging between 75.0 and 155.0 (mean=123.4±16.8, median=122.5). Among the three domains, *Knowledge* emerged with the highest mean (57.8±9.5) followed by *Awareness* (33.1±10.3) and lastly *Attitudes* (32.5±8.6). Between the three domains, the *Awareness* level among FCGs was particularly rated as moderate whereas *Knowledge* and *Attitude* were considered good and positive respectively. Further details are shown in Table 3.

Comparison of AKA profile based on gender, relationship to patient, duration of caregiving and satisfaction in caregiving

Although there is no significant difference in gender, females showed a better score trend in AKA compared to males. Based on relationship to patient, parents reported significantly better in knowledge ($p < 0.05$) compared to others - Table 4. These findings showed that parents have more exposure to epilepsy and the information associated with the disorder. Further results also demonstrated the absence of significant differences among FCGs by duration of caregiving and satisfaction in caregiving. However, carers who have looked after their loved ones within one to ten years and were satisfied with their task showed relatively more favourable AKA scores.

DISCUSSION

In general, all epilepsy patients and their FCGs need to receive some level of education about the disorder, especially as it relates to patients' disease management [10]. They also reported the need of information not only about living a healthy lifestyle and the impact of epilepsy, but also because of the associated physical comorbidities such as diabetes, heart disease and high blood pressure [10]. Hence, they require reliable information on self-management, available social and community resources, support groups and also counselling [11]. Realising the needs for effective educational materials, the development of AnEEV could offer a new direction in the usage of ICT-based delivery tools for carers.

Clearly, our FCGs were already very familiar with the animation and general usage of computer, mobile phones and television which were utilised as our delivery platforms. Since the carers have a better familiarisation with ICT technologies such as computerised-based applications, FCGs had only little difficulties in utilisation of AnEEV [3, 12]. This was especially pertinent since ICT is increasingly becoming part of their routine communication tools for basic tasks such as checking emails, browsing the websites and sending text messages [13].

As the first animated epilepsy educational video in Malaysia, the AnEEV was encouragingly very acceptable by majority of epilepsy carers. That was probably because of its realistic and attractive features which were successful in engaging FCGs during the meeting session. They seemed to enjoy the AnEEV as it realistically depicts their real emotions and daily routine at home. They have gained appropriate knowledge by learning some of the information delivered through AnEEV and this finding showed that it was important to create an attractive, engaging and inventive learning medium compared to using the conventional approaches [4, 14].

With regard to practicality, AnEEV was designed with simplicity and self-explanatory features whereby the information provided was not complicated and presented in a very 'layman' language to facilitate understanding. This simplicity served as an advantage for carers since some may be reluctant to be engaged in such educational programme due to lack of confidence to use the technology [15]. In this matter, AnEEV should be able to expose carers to multimedia applications and empower them to seek information about a particular disease via these popular and convenient techniques [3].

This study has also provided a preliminary insight of AKA level among epilepsy carers in Kuala Terengganu which could act as a very important basis to measure the AKA changes after they have been introduced to AnEEV. The findings were surprisingly in contrast to other public investigations in Malaysia [16,17] whereby, the overall score of our epilepsy carers in Kuala Terengganu was actually good, compared to another report (although their focus was mainly on public and patient perspectives rather than from family carers) [18].

Despite good knowledge level among our carers, their awareness level however was still moderate. Lack of consistent and accurate exposure about this clinical condition seemed to be the main determinant in shaping their apparently still limited attentiveness [19]. Moreover, the existence of false beliefs surrounding this disorder has commonly been spread, worsening the matter and also indicating that epilepsy education has been largely inadequate and ineffective especially in

developing countries [20]. Thus, development of epilepsy health education utilizing a variety of resources such as the internet, computerised software, mass-media and telecommunication systems could play a crucial role in improving awareness in this ICT-driven era [20].

In addition, it was also evident that parents were better in understanding the patient's condition compared to spouses and siblings. Consistent with our findings, other investigations have reported that most parents were very concerned about the unpredictable nature of epilepsy, patients' prognosis and its medicine [8, 21]]. At the time of epilepsy onset and diagnosis, they commonly known as much about epilepsy and were mostly eager to understand more about it in order to maintain patients' health and gained basic knowledge about epilepsy [2, 10]. Furthermore, the caregiving process had apparently motivated them to look after the patient especially if their loved ones were still children who were totally depending on their parents [8]. On the other hand, attitudes towards this clinical condition were reported positive and this favourable outcome may have stemmed from the familiarity of epilepsy people or communities previously affected by similar problem [2, 22].

Overall, we found positive and encouraging evidence with regards to the feasibility, acceptability and practicality of AnEEV and this was vital to ensure the effectiveness of our newly developed health education material. Moreover, AnEEV should be able to empower carers to improve their AKA level in order to provide the best caregiving experience to the patients. Nonetheless, the rather limited sample size from a Malay-dominated setting had somehow prevented us from employing more powerful statistical analyses for broader generalisations.

In conclusion, this study has provided preliminary evidence that the AnEEV was a highly feasible, practical and acceptable educational programme among epilepsy carers. A continuous improvement of this new health educational material for epilepsy could offer an effective solution to enhance awareness, empower knowledge and cultivate positive attitudes among FCGs and patients they look after.

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CONFLICT OF INTEREST

No competing financial interest exists.

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