

Reasons for Non-Compliance to the Headache Diary Report among Migraine Patients in a Tertiary Health Facility: A Qualitative Study

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ABSTRACT

Background: There are limited number of qualitative studies on headache and headache log-book for headache management. This paper aimed to describe the perception towards headache and the headache log-book and to explore reasons for non-compliance on regularity recording information.

Methods: The qualitative study was conducted among migraine patients at the out patient department of the tertiary health facility in Bangkok. Twenty-one migraine patients 20 years of age or older were purposively selected for in-depth interviews. Qualitative guide was developed that includes questions related to perception towards migraine headache and the headache log-book, the reasons for non-compliance on paper based headache diaries recording. Content analysis was used for qualitative data analysis. This study was ethically approved from institutional review board of Faculty of Medicine, Chulalongkorn University Thailand.

Results: Perception towards migraine headache was different and varied among time and situation during the attack. The participants described this condition as the suffering, annoyed, almost dead and fear. Perception among patients on headache log-book grouped in five items; confused, useful, unnecessary /no time to record, similar to homework and over burden. The benefits of headache log-book were useful for patients and physicians for headache treatment. The reasons for not recording the headache log-book were unnecessary, forgetfulness, limited knowledge on recording, no time, unable to remember and lazy/ bored. Ways to remind the recording were include; going back and forth of the headache log-book, writing it down first on papers, record in diary and kept the log-book beside the medicines. The participants stated that they did not know how to start the recording, small spaces for recording and the text is too small to read were the major obstacle. Patients were of suggestions for re-designing the log-book, take a short note, using card/calendar for the recording, check the log-book daily.

Conclusions: The findings allow us to gain understanding how patients described their illness and the reasons for non-compliance on the headache log-book recording. Patient's motivation should be taken into account for benefit of migraine headache management.

Keywords: Headache, headache log-book, non-compliance, qualitative study.

INTRODUCTION

Headache diagnosis is mostly dependent upon information obtained from clinical interviews (1-2). Though, the patients are often difficult to recall precisely their headache characteristics, especially if they have several types of headache (2-3). Sometimes, the clinical features may change during the course of the attacks and present differently in different attack (1-3). Besides the diagnosis of headache, monitoring treatment effect has also a problem if it depends on patient report that has potential for bias and inaccuracy (2-5). Headache diaries and calendars make it possible to record prospectively the characteristics of every attack and this may reduce the recall bias and increase the accuracy of the description (3,5). Thailand is one of the developing countries using electronic, digital or mobile application for medical purposes among the patients and their staff. Chulalongkorn Comprehensive Headache Centre (CCHC), Thailand established in 2000 and using paper headache log-book with two parts for every patient visiting the center. The first part is for education on how to differentiate primary from secondary headache episode; characteristics of migraine, type, treatment prevention, precipitating factors, problems for unsuccessful treatment and discontinuous taking prophylactic medications. The second part is for the history of headache, characteristics, severity, duration, associated symptoms, aggravating/relieving factors, frequency, previous medications, co-morbidities and calendars for prospectively recording. One hundred patients were completed the record, 65 were diagnosed as migraine headache. The average percentage of completeness to the second part of the headache log-book was only 65%. Seven patients (16%) were unable to record the second part and only 20 patients (45%) recorded at least 80%. To improve the completeness of the headache log-book recording, reasons for non-compliance on recording should be elucidated. Moreover, there were very limited number of studies on this topic and there was scarcity of evidence for policy makers in this area. Hence, this qualitative study was conducted with aim to describe the perception towards headache and the headache log-book and to explore reasons for non-compliance on recording information in the headache log-book among migraine patients in a tertiary health facility in Bangkok.

METHODOLOGY

This was cross sectional study conducted with a qualitative approach at the out patient department, Chulalongkorn Comprehensive Headache Centre (CCHC), King Chulalongkorn Memorial Hospital, Faculty of Medicine, Chulalongkorn University. The study population was patients who visited the CCHC and were diagnosed as migraine according to the international classification of headache disorders with age 20 years or older were included. We excluded the ones who were unable to read and write Thai language and who had associated disease. The participants were selected by using the method of purposive sampling with being categorized into four groups according to the percent completeness of the paper headache diaries and calendars as the following: group 1 at least 80 percent, group 2 less than 80 percent illiterate, group 3 less than 80 percent literate and group 4 with zero percent completeness. Twenty-one migraine patients of both genders were purposively selected and finally interviewed on developed question guide. The Chulalongkorn Institutional Review Board approved the study. Patients' anonymity and confidentiality were ensured throughout the research. Method used to generate data was in-depth interview for individuals and the interview was done. Electronic media including audiotape, videotape and word-process transcripts used in data collection process (6-7). Questions guide includes, paper headache diaries and calendars, methods to help memorized headache characteristics, drawback and difficulty in using the diaries and calendars, understandable content in and usefulness of the diaries and calendars and how to improve the diaries. These questions were asked till the saturation of the response (7). Time for each session of interview for individuals was approximately 30-45 minutes and approximately 2 sessions were conducted. Data were analyzed manually using content analysis with thematic analysis technique. The researcher transcribed the transcripts verbatim. Transcripts were coded and recoded through inductive coding for common phrases that discussed the same idea or meaning. Themes were checked against each other and finalized (7). Review of the identified themes and consensus and opinions among research team were used to finalize the appropriate themes.

RESULTS

Twenty-one headache patients were participated in the in-depth interview. Majority 16 were females and about half 11 were married. Most of them were Buddhist, few were Muslim. More than half 15, had bachelor level education or higher. The content analysis from those participated patients could be categorized into seven following themes:

1. *Perception towards migraine headache*

The perception towards migraine headache among the participants was unique and specific to individuals, and in each patient, the perception and feeling were different and varied among time and situation during the headache attacks. In addition, precipitating factors were also different among each attack. The feeling could be grouped into four items like; suffering, annoyed, almost dead and fear.

The "suffering" included both physical and mental status. Some patients could not do fully activities daily living. One patient said "she felt torturous because if headaches occurred during working in the office, she could not work at all and would like to only sleep. After arriving home, she seemed to be exhausted. If the headaches come and gone she felt terrible suffering". The Thai words were "Thoraman)" or being suffering.

"Feeling annoyed" some of participants stated that they feel annoyed was another emotion caused by the headache due to limit doing daily activity. One patient said "...every time, I felt bad after wake-up I had an awakening headache with persistent pain. Sometimes, the headaches relief but come back again that makes me being annoyed and felt uncomfortable". The Thai words were "Ramkhan".

"Feeling almost dead" was an explanation during headache due to pain being torturous and uncomfortable. One patient said "... it seems almost dead, I would like to put my head against the wall because of torture, inability to do anything. The pain is around the eye globes, head pain is all everything bad. I would like to vomit but nothing comes out". The Thai words were "(Meoun ja-tai)". Finally, feeling fear to have headache was perceived by some patients.

2. *The perception towards "the headache log-book"*

The perception towards "the headache log-book" was different among patients. Some patients felt confused why they needed to record. Some patients thought it was useful but some felt unnecessary. The perception towards "the headache log-book" was grouped into five categories; confused, useful, unnecessary and no time to record, similar to homework, and burden. Some patients felt confused with the language in the log- book such as ambiguous, indirect, and incomprehensible. Some said it is useful because physicians would know and understand patient's condition. In addition, it will save time to explain and they did not memorize for the next visit. The log-book would help the patients to recognize what factors triggering the headaches. There were so many factors to trigger the headaches. Some liked the log-book that helps them to know and understand themselves on headache characteristics, precipitating factors and treatments working or not.

3. Reasons for non-compliance on recording the headache log-book

Participants stated that it was unnecessary to record the diary, they could memorize the details of the headache occurred because the headaches did not occur daily. Some participants felt the log-book being like having homework, they had to fill it in the form. Some stated that, they forgot filling diary, they had to recall and fill it only they remember. The participants reported that the main reasons for not complete the log book recording were unnecessary, forgetfulness, limited knowledge on recording, no time, unable to remember, lazy/ bored. Some participants thought it was unnecessary to record on the log-book. Some of them travelled to countryside and left the headache log-book at home. Participants stated that symptoms resolved in a day; there is no need to record log book.

4. Ways to remind own of recording

The participants suggested several ways for enhancing the completeness of record by cross checking, writing on papers, recording diary and kept the headache log-book beside the medicines. Some participants reminded themselves on reading the headache log-book. Some wrote it down immediately by hand on unused paper and then copied it on the log-book. Some participants had their own diary with small size enough to take it with them and recorded. Some kept the log-book beside the headache medicines to record while taking the medicines.

5. Problems and obstacles on data recording

The barriers and obstacles on data recording in the headache log-book reported by the participants includes; too small spaces for data entry, assigned data entry box and color background of log book. Sometimes, the headaches might occur for some consecutive days, the space of each consecutive data entry box with little space would limit the size of Thai alphabets. In addition, the assigned data entry box especially for which drug to be taken was just for one time a day. The color background record is not clearly shown in the log-book. Some participants were unfamiliar with the drug-name listed in the log-book.

6. Suggestions for data recording

The size of log-book should be smaller equal to the size of book-bank. Some suggestions were recording in the unused paper or diary first and then copying to the log-book later. Attending physicians might promptly remind the benefits/reasons of recording for own patients in the log-book. Log-book should be like a calendar or card that can be easy to carry in their pocket. The log-book should have twelve-month recording space for their record.

DISCUSSION

The headache log-book was initiated and implemented in the tertiary health care facility in Bangkok, Thailand. However, one third of the migraine patients in our trail study found the non-compliance of headache log-book recording. This qualitative study was performed to gain more understanding on perception towards migraine and headache log-book, to explore reasons for non-compliance of headache log-book recording as well as to find the way to enhance the completeness of the headache log-book recording among the migraine patients. The study results shown the perception and feeling towards migraine headache were different among time of and situation during the headache attacks (6,7). The participants described it as the suffering, annoyed, almost dead and fear, these findings consistent with previous studies (8-12). Study reported that patients thought that their headaches were severe and disruptive to their lives, it frightens them sometimes, they thought they might death form the severe headache (13). Study shows when patient was annoyed he/she got headache (10). In the contrast, the study found that headache sometimes patients considered them not a serious enough problem to bother the doctor, more than one half of the patients had not consult any physicians within a year (8). In term of perception towards headache log-book, it was categorized into five items including: confused, useful, unnecessary and no time to record, similar to homework, and burden. These findings in line with previous studies (5,14). The study on the Electronic-Diary for Recording Headaches, Triggers, and Medication Use, the long-paper diaries; the participants reported that paper based more burdensome and significantly less easy to use than the e-diaries (14). In addition, a systematic review by team report that headache disorder impose a burden not only on the sufferers' patients themselves, but also on society, economic productivity and health care costs (8). In terms of the benefits of headache log-book recording, the participants reported the usefulness was for themselves and physicians on headache management and further treatment. This findings in line with the statement of the American Headache Foundation to encourage the patients for the recording "Headache Journals: Tracking Your Migraine" (14). One of the major benefits of tracking patients' migraine symptoms is that they will be able to share the information with their healthcare providers, helping to improve their treatment strategies (4,16). The reasons for not recording were unnecessary, forgetfulness, limited knowledge on recording, no time, able to remember and laziness. The findings in line

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with the report on Diaries and Calendars for Migraine (1). For encouragement the migraine patients on the headache log-book recoding, the participants suggested to going back and forth of the headache log-book, writing it down first on handy unused papers, recording first in one's own diary and kept the log-book beside the medicines. In addition re-design the log-book for friendly users was suggested. The limitations of this study, our participants were drawn from patients who had been visited the headache clinic, it may not reflect the experiences of the population. In addition, the sample size, of the qualitative research, was small. However, the aim of qualitative research is not generalizability.

CONCLUSIONS AND RECOMMENDATION

The results of the study allow us to gain understanding how patients describe their illness and the reasons for on-compliance on the headache log-book recording. The rationale for using diaries would be undermined if patients failed to complete diaries according to protocol. To enhance the compliance in completing headache log-book, patients need to be motivated the migraine patients that the diary is a useful resource to ensure the best possible management of their disorder. The diary should come with a set of simple format, but detailed instructions on how to complete each item should be clearly explanation. In addition, Electronic or Internet based should be take it into account for Diary Recording of Headaches.

COMPLETING INTERESTS

The authors declare that they have no competing interests.

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