Spinocerebellar Ataxia Type I (SCA1) Patient Care by Communities in Phayao

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Abstract

Spinocerebellar Ataxia Type I (SCA1) is a genetic disease with minor incidents. Patients with SCA1 express muscle coordination disorder and need for long-term care which eventually affect economic and family life-style. The research objective was to examine the care for patients with SCA1 by families and communities in Phayao Province. The research consisted of three stages. Stage I was a qualitative study from data collected through in-depth interview from five groups of stakeholders which were 1) public health officers 2) local administration organization agents 3) village public health volunteers 4) community leaders, administrators and 5) patients to analyze the care for patients with the disease. Stage II was a quantitative study on care factor analysis by gathering information from 207 related people using stratified random sampling and the data were analyzed through statistic exploratory factor analysis and group conversations to find community-context of care. Stage III was to develop proper care model, implementation of the model, evaluation the model and stakeholders’ satisfaction evaluation.

The results of the study showed that patient care did not gain much attention from the stakeholders due to lack of disease understanding therefore they secluded care. So, the researcher decided to cooperate with related parties to create and develop care system. The care consists of four major factors-in-area home service system management, mental and thinking supporting system, data exchange and care support from related parties.

Public health officers and village public health volunteers are the main mechanisms. It was found that after the model implementation patients received more care than before the model implementation with statistically significance, and the patients were satisfied with the care at medium to highest level.

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In conclusion, chronic disease care development must focus on the understanding about the disease and the long-term care processes of both the family member and community.

**Keywords**: Spinocerebellar Ataxia Type I (SCA1); chronic and long-term patient care

**Rational**

Spinocerebellar Ataxia Type I (SCA1) is a chronic genetic disease causing health problem issues in Thai society. This disease causes both physical and mental problems for the patients. Also, it can lead to economic losses for the patients.

Physical and mental losses occur as the disease usually slow progress. The symptoms may appear in any people aged between 10-70 years old (Rübb et al, 2013). When the patients show their symptoms, they have progressive ataxia, bulging eyes, muscle weakness, spasticity, dystonia and show upper motor neuron lesions (Rübb et al, 2013). The patients eventually turn to be disabled people, they usually confront stress and have adaptation problems. Moreover, they may face economic losses from increasing medical expenses and inability to perform the careers. Hence, Spinocerebellar Ataxia Type I patients need close treatment and community caring as other chronic diseases.

In Baan Tam, Dokkam Tai, Phayao Province, Spinocerebellat Ataxia Type I is discovered. According to the National Health Security Act (2002), Section 47, specify provincial physical fitness fund cover all required targets. The disable according to the Persons with Disabilities Empowerment Act, 2013 should receive treatment. From the screening, patients with special disabilities (muscle weakness and loss of balance) whose symptoms were also shown in relatives were found. So, the cooperation with Faculty of Medicine, Chiangmai University, was done for labolatory test at The Northern Neuroscience Center, Faculty of Medicine, Chiangmai University. Twelve patients were considered to be Spinocerebellar Ataxia Type I. Twenty-five patients were facing muscle weakness and waiting for inability to talk in the future.

From the interviews, the patients had inadequate knowledge about the disease and the care. Not only does the disability had mental impacts, but it also causes problems on welfare requests. The consequent disability conditions do not receive clear diagnosis. Then, proper treatments or disability solutions are insufficient. The patients’ relatives still lack of knowledge about the disease and patient care for their own relatives (Kongtan, 2013). Therefore the society must aware of the importance of caring and take responsibility for its people. The researcher realized that Spinocerebellar Ataxia Type I is a problematic disease for individuals and societies for prevention, treatment and care. So, the researcher was interested in studying care and prevention of SCA1 in communities in Phayao with the following objectives: 1) to analyze situation and context of SCA1 in the communities in Phayao 2) to improve care for SCA1 patients in the communities in Phayao and 3) to examine the result of the care model on SCA1 of communities in Phayao.

**Research Methodology**

Stage 1-Context Analysis of Spinocerebellar Ataxia Type I (SCA1) in communities in Phayao
This stage was a qualitative research with the objective to analyze the context of Spino cerebellar Ataxia Type I (SCA1) of communities in Phayao with the following methodology:

1) Informants including stakeholders for the care on Spino cerebellar Ataxia Type I (SCA1) patients in communities in Phayao. They were the sub-district health promotion hospital director, officer who responsible for chronic diseases, two representatives from local administration organization, two community leaders, two health volunteers presidents, two nurses, two SCA1 patients and their relatives.

2) Research tools: community structure interview issues.

3) Data collection by in-depth interview from the main informants

4) Data analysis using content analysis

Stage 2–Patient Care Pattern Synthesis (Care model)

This stage is divided into two sub-stages as follows;

1) Factor synthesis was a quantitative research. The population was 384 people including public health workers (178 public health officers and village public health volunteers), community administrative workers (38 local administration officer and village leaders) and intimates or relatives (168 patient nurses and relatives). The sampling method used the formula from Yamane (1973). The sample size was 196 people. The researcher magnified the sample size at 10 percent to be 207. Then, the sample groups were selected through stratified random sampling. The research tool for data collection was developed questionnaire. The questionnaire had three parts as follows;

Part I: sample characteristics, part II: Patient care evaluation form using five-point rating scale and Part III: open-ended questions for the respondents to introduce guidelines for patient nurses to deliver high-quality tools for the three professional. Then the index of item objective congruence (IOC) was assessed to evaluate the objective congruency. The index was to be higher than the standard value. The minimum value was 0.5 (Kotakhun, 2016). From the analysis result, IOC Index was higher than 0.5 for each item. When the questionnaire was tested with the unsampled population of 30 people and later calculated the reliability value using Cronbach’s Alpha Coefficient. The coefficient was 0.757. The researcher collected data by interview. Data was analyzed using a computer program with statistical values of frequency, percentage, mean and standard deviation. Mean was used for population characteristic data description. Standard deviation was used for patient care data description. The care factor analysis was done through factor analysis statistics.

2) Format relating to community context detail consideration. The informant group was 11 caregivers who were also in the stage 1 of the study. The research tool was focus group issues. The data collection was done through focus group. The data analysis was content analysis.

Stage 3 – The Data Evaluation: Data was divided into 4 parts which were:

1) The qualitative study using activity observation of the former group in Stage 1. The research tool was weekly behavior record. The data collection was done through observation and record. The data analysis was content analysis.

2) The quantitative study for care progress evaluation. The informant groups were 12 participative patients. The data collective tool was developed questionnaire. The data collection was done through interviews. The analysis was done using computer
program with frequency, percentage, mean and standard deviation for data description. Wilcoxon sign rank test was used for pre and post data difference comparison.

3) The quantitative study for satisfaction evaluation towards patient care. The sample group was the same 207 people in Stage 2. The data collection tool was developed questionnaire with had three parts: Part I: population characteristics, Part II: satisfaction evaluation form towards patient care with five-point rating scale and Part III: open-ended questions for the respondents to introduce their thought as guidelines for nurses to deliver high-quality tools for the three professionals. From the index of item objective congruence, IOC was higher 0.5 for every item. The reliability was done using Cronbach’s Alpha Coefficient of 0.821. The data collection was done through self-report questionnaires. The analysis was done using computer program with mean and standard deviation. Then, the results were compared to the specified satisfaction level.

4) The qualitative study for conclusion. The main informants were those in the Stage 1. The research tool was focus group issues. The data was collected through focus group conversations. The data analysis was content analysis.

Results

1. The contexts and the conditions of SCA1 patients in communities in Phayao Province showed the strengths of patient care including rural communities or primary communities. Most of the population were farmers with high bonding. The community was only 30 kilometers from the city centre. So, the site facilitated the coordination of the provincial units. It had clear village management structure, strong social groups such as village public health volunteering groups, disability groups etc. Also, communities were supported to establish in-area schools including both primary and secondary school levels which promoted community people to achieve compulsory education. Also, Buddhist and Christian institutions were provided to improve the patients’ mental health and original tradition so the locals could do mutual activities. Health personnel both in management and practical levels who permanently worked at Tambon Health Promoting Hospital were able to access communities easily. The locals with faiths provided good acceptance. The weakness was the disease (SCA1) itself which was a rare and newly found disease. The people had little knowledge about the disease. When the disease occurs, it has a few impacts to the society. Thus, the communities did not care for the patients much and did not alert to solve the problems. So, the patients did not receive any chance to be taken care of.

2. Community Care Model Analysis

2.1 Factor analysis

It was evaluated through factor extraction with image factoring and orthogonal varimax to find the number of factors. The factor selection was determined from those with the Eigen value more than 1. In case of care activity selection, the activities with the weight value of 0.3 or above were chosen (Jamornmarn, 2012). The researcher chose the factor weight value of more than 0.5. The factor analysis results were shown in Table 1.
Table 1  Sequence, Important factors for Patient Care’s Name, Number of Factors, Eigen Value and Percentage of Variance of Factors for SCA1 patient care of Phayao (n = 207)

<table>
<thead>
<tr>
<th>Sequence</th>
<th>Important factors for patient care</th>
<th>Number of factors</th>
<th>Eigen value</th>
<th>Percentage of variance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Procedure System Management</td>
<td>7</td>
<td>3.91</td>
<td>24.41</td>
</tr>
<tr>
<td>2</td>
<td>Mental Health Support</td>
<td>4</td>
<td>3.55</td>
<td>22.18</td>
</tr>
<tr>
<td>3</td>
<td>Support</td>
<td>3</td>
<td>1.39</td>
<td>8.66</td>
</tr>
<tr>
<td>4</td>
<td>Care Information</td>
<td>2</td>
<td>1.18</td>
<td>7.39</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>16</td>
<td>10.02</td>
<td>62.64</td>
</tr>
</tbody>
</table>

From Table 1, the patient care factors with Eigen value above 1.0 are four factors with 16 sub-factors and 62.64 percentage of variance. The researcher gave the name relating to sub-factors. Procedure system management has seven sub-factors. Mental health support has four sub-factors. Support has three sub-factors. Care information has two sub-factors.

2. Sub-factors

Factors important for patient care in procedure system management had seven sub-factors with the weight value of 0.68-0.74. Mental health support had four sub-factors with the weight value of 0.64-0.82. Support had three sub-factors with the weight value of 0.70-0.77. Data exchange had three sub-factors with the weight value of 0.73-0.75.

The conclusion presents four factors; (1) Service Delivery - sub-activities are goal setting, appropriate planning, participation appreciation, volunteer grouping, consulting for continuous and sustainable impacts and evaluation follow-ups; (2) Community Mental Support - sub-activities are self-compliments, self-caring, merit-making and social activity participation; (3) Arranging Information-sub-activities are data collection, report and exchange coordination; (4) Resource Rehabilitation-sub-activities are facilities, sufficient budget and balance.

Evaluation & Discussions

The discussion is divided into two dimensions. They are patient care evaluation and satisfaction evaluation. The details are as follows;

1) The pre and post care comparisons: Pre-care evaluation revealed that the overall care was at medium level. In case of each perspective, the evaluations were low to high ones. Post-care evaluation, the overall care was at high level. In case of each perspective, the evaluations were all high. The pre and post care comparisons were different at 0.05 significant level.

2) The stakeholders’ satisfaction evaluation revealed that the overall satisfaction was at high level. In case of each perspective, the evaluations were medium to maximum. The three highest ones were clear goal setting, continuous care and consistent home-visiting with the means of 4.63, 4.59 and 4.57, respectively. The lowest one was sufficient allowance with the mean of 3.50.
According to the factor synthesis, there were four factors – service delivery, community mental support, cognitive and data exchange and support guidelines. In community solution, the management viewpoint is consistent with academic principles. In case of in-depth consideration, many sectors including academic sector (Tambon Promoting Health Hospital), political sector (Bantham Municipality) and people sector (people and community leaders). The sectors related to Prawet’s Triangle Moving Mountain Concept which suggests that solving difficult problems under Thai society context must have three important parts – civil society, NGOs and knowledge/data management (Wasi, 2016). However, the most outstanding unit was public health officers, both the management-level (the director of Tambon Promoting Health Hospital) and the practical-level (chronic disease administrators and village volunteering teams).

Reference


บทคัดย่อ

โรคกล้ามเนื้อเสียการประสานงานจากสมองน้อยและไขสันหลังประเภทที่ 1 (Spinocerebellar Ataxia Type 1 : SCA1) เป็นโรคเรื้อรังที่มีอุบัติการณ์ไม่มากนักแต่ผู้ป่วยมีพฤติกรรมที่มีการเปลี่ยนแปลงอาการอย่างรวดเร็ว และมีความต้องการดูแลและควบคุมโรคต่อเนื่องจากเป็นโรคทางพันธุกรรมและสามารถต่อยคำว่า การดูแลในระยะยาว วัตถุประสงค์ของการวิจัยเพื่ศึกษารูปแบบการดูแลผู้ป่วยโรคกล้ามเนื้อเสียการประสานงานจากสมองน้อยและไขสันหลังประเภทที่ 1 โดยชุมชนในจังหวัดพะเยา การวิจัยออกเป็น 3 ระยะ คือ ระยะที่ 1 เป็นการศึกษาข้อมูลเฉพาะจุดของการศึกษามาตรฐานและกลุ่มตัวอย่างของผู้มีโรค 5 กลุ่มตัวอย่าง เช่น ผู้ที่มีอาการสูงสุดและอาการสุขภาพดีและผู้ที่มีอาการสูงสุดและอาการสุขภาพดีที่สุด ระยะที่ 2 เป็นการศึกษาข้อมูลเพื่อวิเคราะห์รูปแบบการดูแลผู้ป่วยในชุมชน รวบรวมข้อมูลจากผู้มีโรค 207 คน ผู้ที่มีอาการสูงสุดและอาการสุขภาพดี หรือผู้ที่มีอาการดีที่สุดและอาการสุขภาพดี ระยะที่ 3 เป็นการประเมินรูปแบบที่พัฒนาขึ้น และประเมินความพึงพอใจต่อรูปแบบดังกล่าว

ผลการวิจัยพบว่ารูปแบบการดูแลผู้ป่วยในพื้นที่ศึกษาเดิมชุมชนไม่ได้ให้ความสำคัญกับการดูแลผู้ป่วยเนื่องจากไม่เข้าใจโรคและไม่สามารถดูแลผู้ป่วยกันเองได้ ดังนั้นการพัฒนารูปแบบใหม่ 4 องค์ประกอบที่สำคัญ คือ การจัดระบบการส่งเสริมสุขภาพผู้ป่วย ให้มีการสื่อสารกับผู้มีโรค เช่น การทำบันทึกข้อมูลการดูแล การตั้งคำถามเกี่ยวกับการดูแลผู้ป่วย กระบวนการส่งเสริมสุขภาพ เพื่อพัฒนาการดูแลผู้ป่วยที่มีความสุขในระยะยาว กระบวนการจัดการดูแลผู้ป่วยที่มีความสุขในระยะยาว สามารถนำไปใช้ในกลุ่มผู้ป่วยในระยะยาว เพื่อให้ผู้ป่วยมีการพัฒนาการดูแลผู้ป่วยที่มีความสุขในระยะยาว

คำสำคัญ: โรคกล้ามเนื้อเสียการประสานงานจากสมองน้อยและไขสันหลังประเภทที่ 1; การดูแลผู้ป่วยเรื้อรัง และระยะยาว