รูปแบบการสร้างเสริมสุขภาพของแม่ที่ดูแลบุตรที่เป็นโรคธาลัสซีเมีย จังหวัดอุดรธานี ประเทศไทย

HEALTH PROMOTION MODEL AMONG MOTHERS CARING FOR CHILDREN WITH THALASSEMIA MAJOR IN UDON THANI PROVINCE, THAILAND

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บทคัดย่อ

ธาลัสซีเมียเป็นโรคที่มีความผิดปกติจากยีนของเม็ดเลือดแดงซึ่งมีผลกระทบต่อครอบครัว เด็กและระบบสาธารณสุข การศึกษาครั้งนี้ได้พัฒนารูปแบบการสร้างเสริมสุขภาพแก่มารดาที่ดูแลบุตรเป็นโรคธาลัสซีเมีย โดยการวิจัยเชิงปฏิบัติการแบบมีส่วนร่วมเพื่อส่งเสริมการให้ความรู้โรคธาลัสซีเมีย แก่มารดาที่ดูแลบุตรที่เป็นโรคธาลัสซีเมียจำนวน 15 คน ที่อาศัยอยู่ในภาคตะวันออกเฉียงเหนือของจังหวัดอุดรธานี โดยการสนทนากลุ่ม และวิเคราะห์ข้อมูลเชิงคุณภาพโดยการสะท้อนคิดและสนทนากลุ่ม โดยวิธีการวิเคราะห์เนื้อหาและสาระสำคัญ ผลการศึกษาพบว่า มารดายังขาดความรู้ ความเข้าใจเกี่ยวกับโรคธาลัสซีเมีย ผู้วิจัยได้จัดกิจกรรมส่งเสริมความรู้เกี่ยวกับสาเหตุ การติดต่อ การรักษา และการวินิจฉัยโรครวมทั้งให้การสนับสนุนด้านจิตใจ ผลการวิจัยภายหลัง 12 เดือน พบว่า ระดับคะแนนเฉลี่ยด้านความรู้สูงกว่าก่อนทดลอง ระดับความเครียดลดลงและระดับคุณภาพชีวิตดีขึ้น อย่างมีนัยสำคัญทางสถิติ ส่วนข้อเสนอแนะการวิจัยครั้งนี้ประเด็นหลักควรที่จะมีการเสริมสร้างพลังอำนาจและ

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เผยแพร่ความรู้เรื่องธาลัสซีเมีย แก่มารดาต่อไปเพื่อให้เกิดความผาสุกในการดูแลบุตรที่เป็นโรคธาลัสซีเมีย และการนำรูปแบบนี้อาจจะนำไปประยุกต์ใช้แก่กลุ่มผู้ป่วยอื่น ๆ ต่อไป

คำสำคัญ: การวิจัยเชิงปฏิบัติการแบบมีส่วนร่วม, การสร้างเสริมสุขภาพ, โรคธาลัสซีเมีย

Abstract

Thalassemia is a genetic disorder of the red blood cells that also impacts the affected family, child and public health system. This study aims to develop a health promotion model for mothers caring for children with thalassemia major by using participatory action research to promote thalassemic health education. Fifteen mothers with thalassemic children from Udon Thani province, Northeastern Thailand, participated in focus groups. We analyzed the resulting qualitative data using reflexive and critical dialectic through a reiterative process and identified dominant themes. In response to the identified knowledge gaps of these participants, we trained mothers in the cause, transmission, treatment, and prognosis of thalassemia, as well as provide psychosocial support. Maternal scores for knowledge and attitudes increased significantly after 12 months of training, and depression indices decreased following 12 months of psychosocial support. The project activities empowered participants to create and share knowledge, which improved the well-being of mothers caring for children with thalassemia major. This model could be applied in other patient groups.

Keywords: Participatory Action Research, Health Promotion, Thalassemia

Introduction

Thalassemia is a genetic disease. It is a major health problem in South East Asia, especially in Northeast Thailand. It has become the most visible disease about; one percent of the Thai population suffer from the disease. Thailand was found to have 600,000 cases of thalassemia. About 40 percent of the population are carriers and these people may have the possibility of transmitting thalassemic disease (Fucharoen, et al,1991 ; Panich, et al, 1992).

Thalassemia major is characterized by both uncontrollable genetic and biological factors and controllable factors such as therapeutic and lifestyle choices. Moreover, there are also additional factors such as environmental and psychosocial issues (Naidoo J., 1994). Thalassemia poses a heavy burden on unaffected family members, particularly mothers, who struggle to keep up with the health care needs of their children. This is especially true for rural families. However, there are no specific services in the Thai health system to assist such families or mothers. These mothers also have high levels of anxiety and misconceptions about possible transmission to siblings (Prasomsuk, 2007; Subgranon & Lund, 2002).

Participatory action research (PAR) is the principle of a group activity and the participants' involvement in the research process (McTaggart, 1991). The participants are full partners in the research process, while the researcher serves as a facilitator. PAR intends to produce knowledge that can change individuals as well as the culture of the groups, institutions, and societies to which they belong. PAR has been used in nursing in a variety of ways. To enhance nursing autonomy, Street (1997) used PAR as a tool to explore issues of nursing autonomy at a small rural psychiatric hospital. The result demonstrated that they were able to successfully challenge the institutional norms and ideas that limit nurses' autonomy.

Previous study in Thailand revealed that the findings suggested that an increased risk of psychosocial problems in thalassemic children may require psychosocial intervention in order to prevent major psychiatric disorders. Hirunchunha (1998) used action research to develop a care model for caregivers of stroke patients at home. The findings revealed that a suitable care model for caregivers of stroke patients at home consists of caregivers' transformation process, promoting care at home, care-related factors, caregivers' caring competencies, and caring outcome.

Effective health promotion includes attention to family systems as part of the chronic illness model, which requires psychological adjustment on the part of both child and other family members to the disease in question (Holden EW, 1997). Therefore, for the well-being of the entire family, we need to concern ourselves with both physical and psychological health (Sarafino, 1998). In a nurturing family, individuals can attain levels of self-efficacy that are beneficial in the maintenance of good health (Rockhill, 1992). One strategy that could help families with thalassemic children is to promote good health practices at home This is in line with the emergence of the health promotion movement within the past decade, which has led to an awareness of quality of life (QoL) as a broader and more pertinent concept for determining the impact of care-giving on family members (Renwick, 1996).

Several studies demonstrated that PAR was a suitable research approach which contributes to the development of the model of patients and family participation in health care. The empowering and collaborative nature of the research could contribute to an increase in the patients' and families' care abilities and satisfaction with care. Currently, family involvement in child care in a community setting is limited among families with thalassemic children. The investigator expected that the need of the participants will be met, which improve better health practices and the well-being of families with thalassemic children. The outcome of using the health promotion model will contribute additional knowledge to the body of knowledge concerning the quality of life among families with thalassemic children, and also extend the theoretical ideas to empirical testing through a PAR approach that leads to a new trend of health care provision in the institution for Thai society.

However, there is little theoretical information and empirical research regarding a health promotion model of Thai families with thalassemic children. The purpose of this study was to develop a health promotion model of rural Thai families with thalassemic children. It was expected that with a clear understanding of this information, health care professionals who work with these families could support the families in an effective way and make efforts to keep their children as healthy as possible, while maintaining an optimal quality of individual and family life along with social standards and culture in the Thai community. Using this approach, this project aimed to help create knowledge that can lead to action regarding better health promotion practices in rural areas.

Objective

To develop a health promotion model for mothers caring for children with thalassemia major.

Conceptual Framework

The study was guided by the PAR model. PAR is a research method in which a group of people come together to work on a thematic concern through a self - reflective spiral, (“a spiral of cycles of planning, acting, observing, reflecting, and then re-planning”) (Street,1997; McTaggart,1991). The most central feature of PAR is the participation of the community/research subjects themselves in the research process. The participants are full partners in the research process, while the researcher serves as a facilitator of the process. The PAR intends to produce knowledge that can change individuals and the culture of the groups, institutions, and societies to which they belong. These are viewed as a process for personal empowerment, emancipation, and social transformation, which means that political change can be achieved and sustained. It had the following three stages: planning, implementation, and evaluation. The result process was one whereby a community group assumed responsibility and developed the capacity to contribute to their community's development. Rifkin (1990) stated that community participation is concerned not with advanced medical technology but rather with applying tried and tested health care procedures. These procedures must then be applied to the problems of the poor and underprivileged living in rural areas of developing countries. It is believed that only if those who need health care participate in its delivery will there be any impact on the diseases afflicting them. Moreover, only community involvement can ensure that culturally acceptable care is available to those who are at present underserved.

This project was to enable the participants to address the psycho-social, economic, and environmental factors that adversely influence them to promote their quality of life. Therefore, the following were planned and implemented: (1) a workshop for the participants (2) the development of a thalassemic mother's group which included 3 phases as follows: (a) Core team building and group forming; (b) Group activities composed of identifying the problem, seeking for solution to problem, and determining the operation plan; (c) Group empowerment. See Figure 1

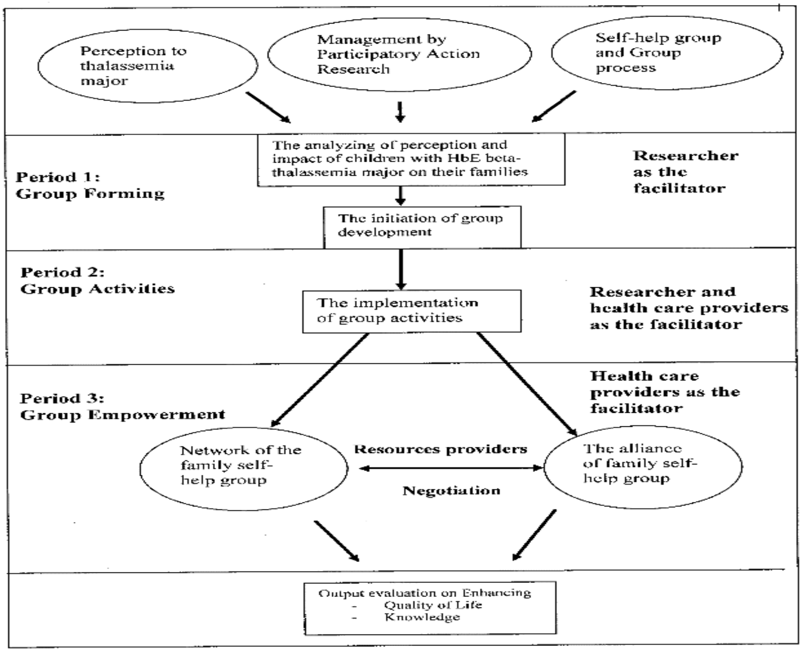

Figure 1 Health promotion model for families with thalassemic children

Material and Methods

The study site was located in Kumpa-wapee District, Udon thani province, which is 560 kilometers northeast of Bangkok. The participants consisted of 15 mothers of 15 thalassemic children aged 2-14 years. The inclusion criteria included families who had a mother whose age ranged from 25-50 years and had taken care of hemoglobin (Hb) β-thalassemia major for at least one year. They were interviewed in-depth, and signed a consent form. At the start of implementing the model, conferences were necessary to identify and discuss the problems of the participants.

Ethical approval (E 460733) for the study was gained from the ethics committee of the faculty of Medicine, Khon Kaen University, Thailand, and individual informed consent was gained from the participants. They were assured of confidentiality and their right to withdraw from the study at any time. They were informed that they could refuse to answer any questions or withdraw from the study at anytime. All data were treated as group information, with no personal identifiers. Direct quotations from participants were ascribed anonymously. Informed consent was also obtained from participants as researchers planned to use some photos in an article for publication.

Methodology

This Participatory Action Research (PAR) was conducted between June and December 2005 in one rural community district in Udon thani province, northeastern Thailand. It followed a mutual collaborative approach between one researcher, two health care providers, and six community leaders. As a result of the PAR, a new thalassemic education training program for groups of thalassemic housewives was designed, implemented, and evaluated. In this PAR, the researchers were concerned with how participants in their communities felt, how they approached problems, and the need to solve their own problems. To enable people to learn these skills, participation is necessary at every step, from identifying problems to solving them. The steps in this study were divided in to three stages: planning, implementing, and evaluating. Questionnaires were composed of a knowledge test, an attitude and depression scale, and also a WHOQOL scale.

Quantitative data was analyzed by descriptive and parametric statistic and qualitative data was analyzed by content analysis.

Results

All fifteen mothers between the ages of 20 to 65 were the primary caregivers of the children. These mothers had experience managing thalassemia for more than one year. Their level of education ranged from the elementary level to the secondary school level (14 elementary, 1 secondary).

The ages of their children when diagnosed ranged from 2 to 10 years. The children were diagnosed as Hb typing Hb β -thalassemia major problem by the doctor.

To allow a good understanding of the mothers' way of thought, the first author lived in the village for one year. In this way rapport could be established, with a progressive decrease in the power gap between the researcher as a scholarly outsider and the participants. The participants played an active role in describing, explaining and demonstrating, while the researcher played mostly a passive role. Methods such as observing, listening, clarifying, taking pictures and recording were used, followed by dialectic and critical reflection. The interactions made the participants recognize the importance of their knowledge and skills.

The participants emphasized the need for involvement and support from the local health center. An important thing that can provide self-confidence to sufferers is knowledge about their condition and things that they could do to assist themselves. The study found that the knowledge of thalassemia of these participants was at a moderate level with a mean score of 10.8 and the range of maximum and minimum was 14, and 8 respectively. Moreover, some of the participants stated that they did not know how to take care of themselves. The researcher took on the role of a teacher who could provide information for them while health professionals at a community hospital trained the participants, and the other training tool used was the handbook on self-care for thalassemic patients. However, one participant indicated that she could not read, while some cases indicated that they could not remember the contents. Consequently, participants liked to consult on a one-problem-at-a-time basis, and that they had the researcher provide this for them. After twelve months, all of the participants were tested on their knowledge again. The findings showed a higher level score with a mean average of 13.9 and 10.8 respectively. Given the small sample size and the result from the Kolmagorov – Smirnov Goodness of fit test showed that scores did not fall within a normal distribution; the Wilcoxon matched pairs signed rank test was to analyze the data. The result shown in Table 1 indicates significant improvements on the measure of knowledge of thalassemia (Z= -3.424, p< 0.05), attitude (Z = -3.046, p<0.05), depression (Z = -3.329, p<0.05) and total quality of life (Z = -3.20, p<0.05). This finding suggests that the training program was successful in enhancing their knowledge of thalassemia.

Table 1 Result of the thalassemic knowledge, attitude, depression and QOL

variable	**Week 1**		**Week 12**		**Z**	**p-value**
	Mean	**SD**	**Mean**	**SD**		
Knowledge	**10.8**	**1.37**	**13.9**	**1.19**	**-3.424**	**0.001***
Attitude	**31.7**	**4.11**	**38.4**	**3.04**	**-3.045**	**0.002***
Depression	**41.6**	**9.40**	**35.5**	**9.64**	**-3.329**	**0.001***
QOL	**78.07**	**8.55**	**81.27**	**9.53**	**-3.329**	**0.001***

*p<0.05

Discussion

The group of thalassemic housewives was gradually formed and accepted by the community. It needed authorities to organize the group activities. The motivational climate was the key for involving thalassemic families and their neighbors in the community to participate in the group. The benefit and motivation of participation led the members to change their opinions on thalassemia that affected their families and children. Thalassemic prevention and control, occupational development, and dissemination of thalassemic knowledge to young students were effectively involved by the thalassemic housewives’ group and the community leading to a greater understanding of thalassemia and of the quality of life of the thalassemic group in their community. As a result, there was an increase in the confidence of the thalassemic housewives’ members in collecting and collaborating to participate in the activities. According to the suggestion by Meissen GJ (1994), a family self-help group which developed through all levels of the community helped to create a sense of community. Solidarity and a sense of shared purpose were critical elements in sustaining change among human resources.

The predominant structures of the development of the thalassemic housewives group were decentralized responsibility and participation, which were considered by the participants. Family members, family nurses, primary health care workers, a community committee and local community organizations worked towards roles and a goal, and aimed to enhance the quality of life of these families. The decentralized responsibilities of stakeholders at all levels were fundamental to their daily lives because they didn’t have much time to concern themselves particularly with the group’s development.

In this study, the development of the thalassemic housewives group took about one year. The first two months were used to study the thalassemic family context. Periods for self-help group development took approximately six months. Output, impact, and outcome evaluations took about three months. The group activities could not be rushed; it was gradually developed and waited for the appropriate time when it was accepted by group members through partnerships and mutual responses among the stakeholders. According to the PAR (Street, 1997), it was a process of adult learning and a community development approach which involved, facilitated, and enabled factors in community participation. Stakeholders became consciously involved in their own behaviors through a partnership, accepted greater responsibility for well-being, and increased the level of sustaining interest and enthusiasm among them.

Factors determining the success of the model

Several important factors, indicators, and dimensions of the thalassemic housewives' group were used to determine the success of their activities in this study.

1. Member of thalassemic housewives' members

The quantity of group members was an indicator of group success. The more members the group had, the more number of participants were emerged. Although some members refused to help or ignored others at the beginning of the group setting, the group process gradually socialized them to adjust their behaviors or discarded them from the group. Additionally, group members who were role models could increasingly attract others to join the meeting. The capabilities, skills, knowledge, thought, and power of the members were the qualitative indicator of the thalassemic housewife group's development. These qualities affected the experience and learning of the members. The members who had high levels of capabilities, skills, knowledge, thought, and power often had more confidence to work and advocate others to join them, and to lead others to develop their capabilities.

2. Quantity and quality of group activities

The numbers of activities, especially the successful and progressive activities, affected the motivation of group members. They aided them to work towards the group goal. The activities of the group members progressed in the same direction. Group activities were determined by participants on an individual level. The new activities created by group members indicated their potential, as well as resources, place, and time management. At the beginning of meetings, group activities were initiated by the researcher and health care sectors. The activities in the last period were preceded by health care providers, family members, and a community committee. In addition, some activities organized by family members during crisis were the indicators of group maintenance. For example, although the resources allocated by local authorities for maintaining the group were sufficient, the group members agreed to sacrifice their budget and sought for help from other sectors.

3. Networks of the self-help group

It was noticeable that the family self-help group in their community had the dimensions of self-reliance and mutual help among networks. Members of the self-help group mutually practiced self-help activities to achieve their goal. The participants were group networks that predominantly help the community to be capable of collaborating, negotiating, and accessing external resources. Also, the number of sectors which participated with the group indicated the quantity of networks, and the character of the networks pointed to the quality of the family self-help group.

4. Status of thalassemic housewives’ group in the community

This indicator was assessed from an external reference. It was different from the three indicators mentioned before which were assessed by group members in the community. Once the family self-help group had more members, it was gradually participated in, negotiated, and run by its members. These members were accepted by stakeholders in the capacity of group collection, negotiation, resource mobilization, and community development. The family self-help group in the community gradually developed its own power and freedom to determine the direction of its development. They shifted or enhanced their capacity to control what had previously been uncontrollable, influencing people to participate in the self-help activities and increasing the capacity to prevent thalassemia in the community. Consistent with the recommendation by Wattana C. (1997), the maintenance of group activities depended on the capacity to modify its status to have an effective function in responding to community needs under the changed environment.

In summary, the most important element in the thalassemic housewives group's development was the increased consciousness of occupational promotion and thalassemic prevention. As a result, the family and the community increased their capacity to manage these activities, as well as to collaborate with local organizations in planning, implementation, and evaluation based on community needs assessed through participatory research.

Conclusion

This study showed changes among the participants through PAR. The findings indicate the relationship between empowerment and health, namely, that self-understanding and self-confidence empower individuals and communities, and that empowerment in turn enhances health promotion. PAR would appear to be a valuable approach in facilitating this outcome, striving to balance the goals and objectives of research with action.

Recommendation

It was found that the principles of health promotion for the participants in this study could be proposed as suggestions for the practice of health promotion for health services overall.

Policy level Every health care center should formulate thalassemic policy concerning empowerment programs for thalassemic patients and thalassemic families. The management of psychosocial problems in thalassemic families should be included in the guidelines for the management of the impact of thalassemia.

Action level Workshops on thalassemic training should be held and revised regularly for medical health team workers, especially health educators and nurses to provide appropriate techniques to the thalassemic children and their families, and to promote participatory learning in the health promotion of thalassemic families. It was found from this study that participation in group settings among thalassemic families would yield positive effects on these participants. They gained more appropriate thalassemic knowledge, skills, and attitudes toward the prevention of thalassemia occurring in their community. At the same time, they should gain skills of participatory learning in order to provide adequate and continuous social support to each other, leading to the enhancement of their quality of life in the near future.

Recommendation for further study

Further study, such as the design and development of a health promotion model for thalassemic families, would be conducted in different areas of the province. The exploration of the quality of life among families with children having thalassemia should be designed for generalization with respect to other areas.

Limitation of this study

The study was undertaken in one specific area with a small sample size, thus the model might only be appropriate for this group. The time for implementing the program might be shortened to evaluate the quality of life among thalassemic families. Resource planning, such as financial support, was limited in this study, and human resources should be available as a reserve source in the event of urgent problems occurring.

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References

Fucharoen, S. et al. (1991). **Prenatal diagnosis of Thalassemia and hemoglobinopathies in Thailand: Experiments from 100 pregnancies. Southeast Asian Journal of Tropical Medicine & Public Health, 22**(1), 16–29.

Hirunchunha, S. (1998). **Development of care model for the caregiver of stokes patients at home**. Doctoral dissertation in Nursing, Faculty of Graduate Studies, Mahidol University. (in Thai)

สุดศิริ หิรัญชุณหะ. (2541). **การพัฒนารูปแบบการดูแลสุขภาพที่บ้านของผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง**. ดุษฎีนิพนธ์ปริญญาเอกสาขาพยาบาลศาสตร์, บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล.

Holden, E. W. et al. (1997). Controlling for general and disease-specific effects in child and family adjustment to chronic childhood illness. **J Pediatr Psychol, 22**: 13-27.

McTaggart, R. (1991). Principles of participatory action research. **Adult Education Quarterly, 41**(3), 168-187.

Meissen, G. J., & Warren, M. L. (1993). The self-help clearinghouse: A new development in action research for community psychology. **Journal of Applied Behavioral Science, 29**(4), 446-463.

Naidoo, J., & Willis, J. (1994). **Health promotion foundation for practice**. London: Bailliere Tindall.

Panich, V., Pornpatkul, M., & Sriroongrueng, W. (1992). The problem of thalassemia in Thailand. **Southeast Asian Journal of Tropical Medicine & Public Health, 23**(1), 1-6.

Prasomsuk, S., Jetsrisuparp, A., Ratanasisi, T., & Ratanasiri, A. (2007). Lived Experiences of Mothers Caring for Children With Thalassemia Major in Thailand. **JSPN, 12**(1), 13- 23.

Powell (Ed). **Understanding the self-help organization: Frameworks and findings**. California: Sage publication.

Renwick, R., Brown, I., & Nagler, M. (1996). **Quality of life in health promotion and rehabilitation: Conceptual approaches, and application**. Thousand Oaks, CA: Sage.

Rifkin, S. B. (1990). **Community participation in maternal and child health/ family planning programmes: an analysis based on case study materials**. Geneva: World Health Organization.

Rockhill, V. A. (1992). **Family background and Personality factors influencing Health related attitudes and behaviors toward medical treatment**. Ph.D. Thesis, Faculty of Health Sciences, University of Rhode Island.

Sarafino, E. (1998). **Health psychology: Bio- psychosocial interaction**. 3rd ed. New York: John Wiley & Sons.

Subgranon, R., & Lund, D.A.(2002). Maintaining caregiving at home: A culturally sensitive grounded theory of providing care in Thailand. Journal of Transcultural. **Nursing, 11**(3), 166-173.

Tedsiri, C. (1994). **Buddist and Psychological characteristics of parents as related to child care illness in Thalassemic children**. Master’s thesis in Behaviral Science, Institute of Behavior science Research, Srinakarin Taravirot University. (in Thai)

ชุติมา เทศศิริ (2537). **ลักษณะพุทธศาสนาและจิตลักษณ์ของบิดา มารดาที่เกี่ยวข้องกับพฤติกรรมการดูแลบุตรเจ็บป่วยเรื้อรังด้วยโรคธาลัสซีเมีย**. วิทยานิพนธ์วิทยาศาสตรมหาบัณฑิต มหาวิทยาลัยศรีนครินทรวิโรฒ.

Street, A. (1997). **The Participatory Action Research Process for Clinical Nurses**. Unpublished manuscript.

Wattana C. (1997). **Model development for participatory caring relationship between nurses and patients to enhance self - care abilities in Kanghangmaew Hospital Amphoe Kanghangmaew Changwat Chantaburi**. Master's thesis in Nursing, Faculty of Graduate Studies, Mahidol University. (in Thai)

ชดช้อย วัฒนะ (2540). **การพัฒนารูปแบบการดูแลอย่างมีส่วนร่วมระหว่างพยาบาลและผู้รับบริการในการส่งเสริมการดูแลตนเอง โรงพยาบาลแก่งหางแมว จังหวัดจันทบุรี** วิทยานิพนธ์พยาบาลศาสตรมหาบัณฑิต มหาวิทยาลัยมหิดล.