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A Model of Home-Based Care for People with Disabilities: Better Practice in Rural Thailand

C Wanaratwichit, D Hills, M Cruickshank and B Newman

Abstract

Background and objective: People with disabilities living in rural areas often require considerable support to meet their complex needs. This study investigated a best practice model in home-based care for people with disabilities in rural Thailand.

Design and Setting: A case study method was adopted to investigate a best practice model of home-based care for people with disabilities in Nakhonchai District, Phitsanulok Province, Thailand. Data were collected from 30 participants through in-depth interviews, focus groups, direct observation and document analysis. Content and thematic analyses were conducted for qualitative data. The Wilcoxon Signed-Rank test was used for the outcome measurement of activities of daily living (ADL) scores.

Results: This model of home-based care for people with disabilities, as an integrated network model, brings together the community, health professionals and other organisations. The role of trained community

health volunteers was mainly to deliver home-based personal care for people with disabilities, while health professionals focused mainly on controlling the quality of care, managing the knowledge and skills of volunteers, and co-ordinating the network. The difference between ADL scores before and after the implementation of the model (n=20) was statistically significant ($p < 0.01$).

Conclusion: This best practice model of home-based care for people with disabilities in rural Thailand shifts responsibility in the main service decisions from professionals to the community and other stakeholders and engages and empowered all stakeholders in the provision, co-ordination and management of care.

Abbreviations: ADL – Activities of Daily Living; CUP – Contracting Unit for Primary Care; HBC – Home-Based Care; PwD – People with Disabilities.

Key words: home-based care; people with disability; integrated care.

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Introduction

Since 2002, healthcare system reform in Thailand has emphasised the provision of primary healthcare through the Contracting Unit for Primary Care (CUP) network at the district level to improve healthcare accessibility, especially for more disadvantaged people such as people with disabilities (PwD). The committees of CUPs manage their population health based on the budget provided from the National Health Security Office.

The healthcare for PwD has depended on the health policy and the provision of the *Thai Rehabilitation of Disabled Persons Act* (1991). [1] However, the accessibility of health services remains insufficient, [2] especially in relation to physical rehabilitation services and the complications resulting from accessibility to continuing physical rehabilitation. [3]

Establishing appropriate patterns of care for PwD has been problematic because of a lack of understanding and poor information sharing about the rehabilitation process by health professionals, [4] funding, professionals' knowledge and attitudes, communication gaps and health system failures. [5] The main problems for PwD are, living with limited movement and subsequent difficulties with self-care [6] and that they require home care from a nurse. [7]

As a consequence of this gap in the evidence base, an existing best practice model of home based-care (HBC) for PwD in rural Thailand was investigated, focusing on the context, processes, mechanism of management and outcomes for disabled people who have severely limited movement.

Methods

A case study design [8] was used to explore and describe a HBC model selected from 43 districts in health service region two of Thailand, which was identified as representing better practice in a rural area of Thailand by the National Health Security Office. The unit of analysis was a Nabou sub-district Health Centre and its stakeholders, Nakhonchai district, Phitsanulok Province in northern Thailand. The analyses were conducted within the framework of established concepts of HBC [9,10] and the district health system, [11] in accordance with healthcare system reforms. Realist evaluation [12] was applied to analyse the relationships between the issues of concern.

In this mixed-methods study, qualitative data were gathered in in-depth interviews [13] and focus groups with four primary care providers, four members of the district health management team, one leader of local government and three village leaders, one supporting officer at the provincial level, one supporting officer from the National Health Security Office, as well as 20 disabled people and five family members. Every participant had a role focused on disabled people in the study area for at least one year. In addition, eight trained community health volunteers who delivered care and seven healthcare workers participated in focus group interviews. [14] The in-depth interviews began with semi-structured questions and data were collected to help clarify the process and program of HBC, the participation of stakeholders, the mechanisms of management, the outcomes for disabled people and the socio-cultural context of the services and outcomes.

The focus group interviews investigated three issues – the experiences and the achievements of HBC, and the mechanisms for its management.

All data were fully recorded by electronic recorder and the main points were noted. Additionally, a participant observation check-list was utilised by researchers in the community setting. The qualitative data were analysed using content analysis [15] and thematic analysis. [16] All records were read and reviewed several times. Coding for the process and management of care were undertaken within the framework of HBC principles and the district health system, utilising realist evaluation.

In the quantitative component of the study, the health record form of each person with a disability was used to collect data on care provided and the score of daily activity was determined from this document. Descriptive statistics were used for quantitative data and the Wilcoxon signed-rank test was employed to examine the difference between functional measures and activity of daily living scores, before and after the introduction of HBC services. Post-intervention measures were conducted one year after commencement of the HBC model. Permission to conduct the study was provided by the Human Research Ethics Committee of Naresuan University, Naresuan, Thailand.

Results

Two primary themes emerged from the qualitative analyses, reflecting the structures and characteristics, and the process of the model of HBC for disabled people in rural communities of Nabou sub-district. A third theme, drawn from the quantitative analysis, demonstrated the positive functional outcomes for PwD receiving care and support.

Community context

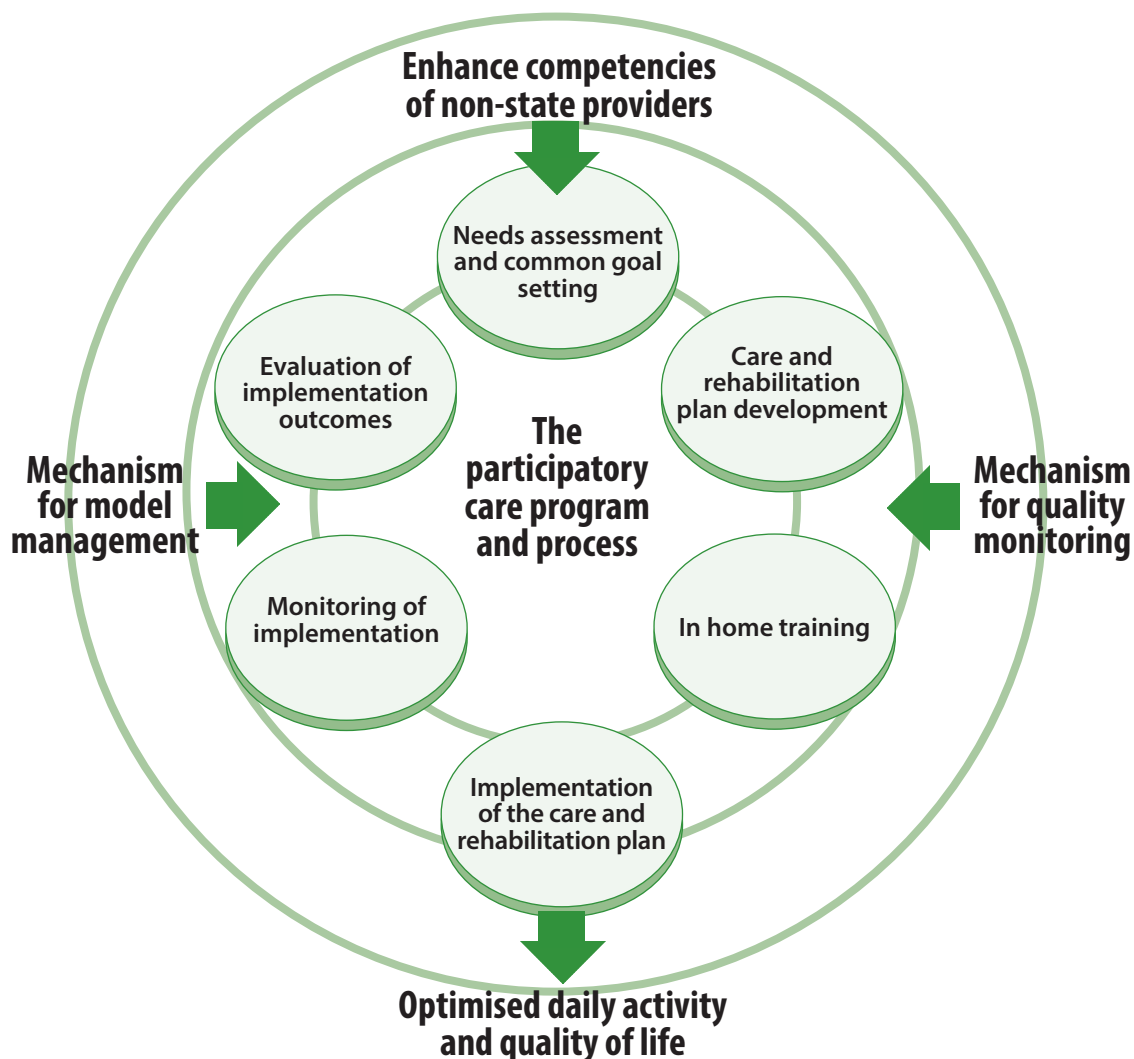
This community had high social capital, social kinship, good relationships, high social participation, helping each other, community member trust and respect in leaders. Village leaders had the vision to develop the community's health. This led to the willing participation of the community in HBC for PwD.

An integrated network model

Firstly, the characteristics of the HBC model were identified as an integrated network model (Figure 1), integrating the team and the care, and incorporating care between the health and social welfare services among the inter-professional collaboration and community.

They were found to be working together, with the Health Centre as the coordinating centre. A key instrument through which care, support and resource allocation could be facilitated was a healthcare record toolkit for healthcare. The nurse designed record enables the recording of health volunteer actions and achieved outcomes against planned goals or activities, including aids to daily living (ADL).

Figure 1. The better practice home based care model for people with disabilities in rural Thailand



The care program was found to focus mainly on health and functional rehabilitation, and mental and spiritual support. Nursing care was provided based on the presenting health problems. There was less focus, however, on physical environments and occupational support in the home.

A participatory care program and process model

A model of care was identified and operationalised within the framework of a six-stage process of participatory care, and three primary management context factors leading to the optimisation of the daily activities and quality of life of PwD in this rural setting (Figure 1).

The six-stage process of participatory care comprised:

Needs assessment and common goal setting

Health professionals and community stakeholders visited PwD in their home to assess their health, social and environment needs and potential to engage in daily activities for setting common goals.

The nurse and physiotherapist came to visit the disabled person with us, assessed their ability of movement, discussed with us and advised us what we can do for the person with disability. However, it was also with consensus among the disabled person and their family.

[Community health volunteer – translated from Thai]

We [the stakeholders] reached consensus in developing the rehabilitation plan. It is very important because it leads to care participation among the stakeholders.

[Physiotherapist – translated from Thai]

Care and rehabilitation design following on from needs analysis and goal setting, care and rehabilitation were designed through collaboration and involvement of all stakeholders.

In home training

Trained community health volunteers, PwD and their family members were trained at home again by the physiotherapist, based on the individual person's needs and assessed potential. This training not only improved the self-confidence and skills of the community health volunteers, it also enhanced the disabled person's belief and trust in the care provided.

The physiotherapist comes again to teach us at the home of the disabled person, based on the problem of the people, which gives us high self-confidence to look after the disabled person and they also feel confident.

[Community health volunteer – translated from Thai]

We [community health volunteers] were very glad that the physiotherapist and nurse trained us again when they visited at the disabled person's home. I felt confident to look after the disabled person, and they perceived that we were well-trained.

[Community health volunteer – translated from Thai]

Implementation of the care and rehabilitation plan

Most home care was provided by the trained health community volunteers, twice each week, and comprised guiding and supporting the person in undertaking exercises, measuring vital signs and providing mental support. Supported activities also extended to family members. In addition, other stakeholders were engaged in service provision. The 'elderly volunteers' supported mental health and the Thai massage volunteer visited based on the person's needs and care plan.

The people who continuously look after the disabled people are community health volunteers. They also continuously report or tell us about any changing condition of the disabled people when I haven't visited them.

[Nurse – translated from Thai]

I come here two times per week to help the disabled person to exercise, give encouragement to their family.

[Community health volunteer – translated from Thai]

At a co-ordination and leadership level, the local government leader co-ordinated and supported vehicles for transportation to the hospital, social and welfare support and some home modification services, while the provincial public health office, the district public health office, the National Health Security Office and the community hospital provided relevant resource support, including in relation to budget, materials, knowledge and health policy, according to their mission.

Monitoring of implementation

Every two weeks, the health professionals visited the person with disabilities, to monitor and evaluate the home care practice of the volunteers, assess outcomes, and where required set new goals and plans, provide direct care and rehabilitation interventions, and provide further training for the community health volunteers.

The nurse and physiotherapist go to a disabled person's home every two weeks to teach us about nursing and rehabilitation again as well as monitoring our performance.

[Community health volunteer – translated from Thai]

I and the nurse in the Health Centre always went to a disabled person's home to provide care and monitor the rehabilitation provided by the volunteers. If it is not successful we take action to improve the plan or care provided.

[Physiotherapist – translated from Thai]

Evaluation

Participatory evaluation by stakeholders was undertaken when visiting the disabled people at home and decisions were made in relation to referral, such as to the community hospital or to other relevant organisations dependent on the problem(s). Decision-making then returned to reassessing needs and common goal setting, as required.

The three primary management context factors leading to the optimisation of daily activities and quality of life of people with disabilities, highlighted in Figure 1 comprised:

Enhancing competencies of non-state providers

Before the instigation of the HBC model, a one-day training session was provided by the district health system committee for the selected non-state providers, including the community health volunteers, who had more skill in nursing and were willing to help other people, and family members of PwD. They were trained in relation to movement and exercise skills as basic rehabilitation.

We select five community health volunteers per village, who have more skill in nursing and are willing to help other people, to train in the principles of rehabilitation for disabled people and, at the same time, we also trained the disabled person's family.

[Nurse – translated from Thai]

Mechanism for monitoring the quality of care and rehabilitation

A key way of monitoring and controlling care in the non-health professional group was in a case conference. A monthly conference was held among community care workers, where a complicated case was selected to discuss, share and exchange experience and knowledge, and solve

problems collaboratively. This mechanism depended, somewhat, on the commitment and co-ordination skills of the health professional in the Health Centre. Another way of monitoring of care quality was visiting the person with disabilities at the same time as the volunteers, reviewing their performance 'on the job'.

Every month the community health volunteers come to the Health Centre for a meeting with the health professionals and talk about the health condition of the disabled people, successes, and problems of the disabled people. In complicated cases, we discussed together. This process is led by the head of the Health Centre who is highly skilled in running the meeting.

[Nurse – translated from Thai]

Mechanism for model management

The mechanism for managing the implementation of the model of HBC in rural communities consists of three components. Each had a role in enhancing the accessibility and integration of care and decreasing its cost. Firstly, a steering group consisting of the main health professionals, physiotherapist and nurse who led and drove the care process was established. They worked together to plan and monitor the accessibility, provision and quality of HBC. Secondly, sharing the lessons learned in the implementation of all aspects of the model among all stakeholders facilitated ongoing HBC planning and delivery. This strategy was an important instrument in supporting the participation and partnership of all stakeholders, especially at the community level, in both decision-making and implementation of the model. Thirdly, the role of the Health Centre as the Co-ordination Centre was central in managing the overall

implementation of the HBC model, providing a meeting venue, a centre for exchanging and distributing data on disabled people to stakeholders, coordinating care and resource support from other organisations, and the central hub for facilitating and monitoring care. In this way, the Health Centre was able to reduce gaps in care provision and increase the participation of the community and the collaboration among organisations. The success of the Health Centre as the co-ordination centre was attributed to the management skills, experience and social relation of its health professionals.

Functional outcomes of model implementation

Quantitative measures in a sample of 20 PwD showed a demonstrable difference in outcomes following the instigation of the HBC model. Firstly, as shown in Table 1, while all people with disability received a health assessment, few had received other care and self-care interventions prior to instigation of the HBC intervention.

The mental support of care providers and other stakeholders, and the positive impact of exercise or rehabilitation were fundamental to the ongoing morale and intention of the PwD to achieve increased levels of self-care, well-being and improved quality of life.

Previously, she only laid there and could not do anything. We had to help her for eating and taking a bath. After many people came to visit, to help and teach her to exercise, she was better. Now she can eat and move to do many things by herself.

[Family caregiver (speak and smile) – translated from Thai]

Table 1. Comparison of performance after and before implementation of home-based care for people with disability

CARE AND SELF-CARE INTERVENTIONS	BEFORE (n)	AFTER (n)
Health assessment	20	20
Care based on problems or needs	0	20
Teaching and rehabilitation by health professional at home	0	20
Teaching /assistance with rehabilitation by volunteers at home	0	20
Mental support	0	20
Social and welfare support	7	20
Mobility aids support	3	20
Did exercise or rehabilitation by disabled people	0	20
Correctly did exercise or rehabilitation by disabled people	0	20

Yes, now I can do it and every morning I have to exercise before I move from my bed ... because it is good for my movement, so I try to do it every morning.

[Disabled women aged 68 years – translated from Thai]

Secondly, using the Wilcoxon signed-ranks test, a statistically significant improvement in the pre-post intervention Activity of Daily Living scores was evident (n=20, Z=-3.378, p<0.01).

Discussion

The great achievements of the HBC model are high accessibility to home care and enhanced self-care, well-being and quality of life for PwD. This is in line with the broader goal of HBC models, which is to help family caregivers and sick family members maintain their independence and achieve the best possible quality of life. [10,17]

Health policy and payment methods of top-up funding for service provision and utilisation are important because they affect the design of the care model. The more that PwD access services, the greater the compensation to the district health organisation. The social context – social capital, strong community – also supports the design of the participatory process of the model.

The characteristic of the model was integrated network care among stakeholders in all sectors according to the WHO concept of primary healthcare as an integral part both of the health system and overall of the community as well as integral to curative care, health promotion, prevention and rehabilitation. [18] Although the model involves integrated care, the care providers still mainly emphasise health rehabilitation because of the specific problems with physical movement experienced by PwD. Mental and spiritual support is also important. People who have good mental health can make the most of their potential and cope well with life and its changes. [20]

The PwD in the current study, however, did not receive much support in relation to the physical environment, such as helping technology, which allows them to have independence, maintain good health and prevent social isolation. [21]

While the functioning of the integrated team as a network in the current model is generally aligned with the principle of the HBC program for people living with HIV/AIDS, which is to build and support referral networks and collaboration among participating entities, [22] key stakeholders in this network included the relevant organisations and the coordinator, whose role is fundamental to linking the various members of the network. This is different from the care

providers for HIV in a household that consists of community care workers, primary (family) caregivers and care recipients. [17] The more complex needs of the PwD require more diverse input from a multidisciplinary care team.

Inter-professional collaboration led to the achievement of desired care outcomes. This is similar to the effectiveness of inter-professional care working for older people living in the community, where more than half reported improved health, functional, clinical, process outcomes and patient satisfaction. [23]

Unmet needs are still a problem for many PwD. [24] In the current study, however, the needs of PwD could mostly be met because of the process of case management that was, at its core, based on the problems and needs of each of the PwD and because it involved all stakeholders in working toward the improvement of patient outcomes. [25]

Trained community health volunteers working as a friend and coach of PwD's families were also fundamentally important people for the provision of continuous HBC. This finding is similar to a study which found that the village health volunteer is likely to be a key person for improving the accessibility to home healthcare for PwD in a rural community. [26]

On the job training enhanced health volunteer competencies and greatly enhanced the quality of care to the PwD in their homes. Training can reduce the barriers to care, by reducing gaps in communication, knowledge and skills, [5] and reducing overall costs of training due to less time spent retraining. [27] Additionally, participatory monitoring of the health volunteers providing care in the home, in conjunction with the regular case conferences, enhanced continuous learning, further strengthening care quality.

Overall, these components influenced the quality of care and level of community participation. [28] This finding indicates that the HBC process still needs health professionals, with their specific skills, to be engaged in solving problems. It is different from the principle of HBC that focuses on empowerment of family caregivers or families and communities to care for PwD. [9, 29]

A key mechanism for the model management, in the current study, was the steering team working in collaboration with the district health system, in accordance with the role and responsibilities of the district level in community HBC. [30] The steering team could not make decisions in relation to supporting resources as this was under the control of a committee of district health management.

The most important mechanism of the model management, however, was the Health Centre Co-ordinator, at the sub-district level. They could sustain and co-ordinate the whole model to achieve the optimal levels of participation in care and maximise health outcomes. The successes of these mechanisms are attributable to the individual skills in the Health Centre. Management skills, especially, are needed. According to Sunitha Dookie and Shenuka Singh, strong leadership, a strengthening of the current district health system and a greater emphasis on health promotion, prevention along with community participation and empowerment was required in a well-functioning district health system for the re-engineering of primary healthcare. [31]

Study limitations

The primary limitation of this study is that it examined only one unit of best practice in the north of Thailand. The research would benefit from further, similar studies elsewhere.

Conclusions

The aim of this study was to explore a best practice model of HBC for disabled people in rural Thailand. The model shifted responsibility in the main service decisions from professionals to the community and other stakeholders in an integrated care network. Mental and spiritual support was key to promoting self-care and decision-making for PwD.

Co-ordination at the Health Centre level was also fundamental in ensuring continuous HBC for PwD, with care provided by community health volunteers under the direction of health professionals. Overall the care model led to optimal outcomes for PwD and their families.

Continuous training and support for non-state providers and community volunteers is also important. Capacity building for health professionals also needs to be considered, especially in relation to enhancing rehabilitation and management skills.

Overall, the model was built on high social capital and a strong community context, performance-based payment methods and targeted policy from the national level. Health policy and social context are key components of a best practice model of HBC for PwD.

Competing interests

The authors declare that they have no competing interests.

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